

**Medical Providers and the Birth to Three Early Intervention Program:
Key partners in the need for system changes to improve outcomes for children**

Summary Report and Recommendations

From

The Medical Provider-Early Intervention Partnership Project
A project of the SOAR Prevention and Early Intervention Action Team

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Jill Sells, MD

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Dear Reader:

The report you are about to read is the product of a project initiated by the SOAR Prevention and Early Intervention Action Team in King County Washington. SOAR is a community collaborative focused on the success of children and youth, ages birth to eighteen, in King County. It is governed by a partnership council of stakeholders and leaders from local organizations, government, businesses and community coalitions. Information about SOAR's Prevention and Early Intervention Action Team can be found at: http://www.childrenandyouth.org/actionteams_earlychildhood.html

SOAR is interested in improving the school readiness of young children and has established goals to help achieve optimal outcomes for all children. One of these goals is that **Children and families most in need of services receive high-quality, affordable and culturally competent services early**. This project and its report seek to help address this goal.

King County data suggest that many young children exhibiting or at risk for developmental delays are either not being referred at all, or are not being referred early enough, to the county's Birth to 3 Early Intervention Program. SOAR's Prevention and Early Intervention Action Team would like to implement strategies which will improve the timeliness of appropriate referrals. The Action Team would specifically like to improve referrals from primary care medical providers.

Because many previous efforts to change physician behaviors in King County, Washington state and elsewhere have been challenging, and often have not achieved desired goals in a sustainable way, the author of this report was engaged to advise the Action Team via this project. **The intent of the Medical Provider-Early Intervention Partnership Project is to build partnerships with medical providers that encourage and facilitate their ability to successfully identify and refer families into early intervention services (birth to 3); and set the stage for wider implementation of successful partnerships throughout King County.**

It is the hope of all who contributed to this report that the information and recommendations provided here will prove useful for the next phase - implementing strategic partnerships between the Early Intervention Program and medical providers to meet the needs of young children and families.

Respectfully submitted, Jill Sells MD

Acknowledgements

The author would like to extend her deep appreciation to all the individuals who contributed to this report. While their input is for the most part combined with others and not identifiable, their names appear in the reference section. Without the candid and thoughtful involvement of those who were interviewed, this report would not be useful. It is never easy to share personal, agency, or system shortcomings publically. Yet the willingness of all involved in this work to admit what is not working well, and to offer suggestions for how to improve processes, is a testament to how deeply they all care about the children in King County. The work to be done to create an Early Intervention Program that works well with physicians and addresses the needs of all children at developmental risk is substantial. There is no doubt, however, that meaningful progress can be made by strategically engaging the collective wisdom and commitment of early intervention and medical providers, and those who support their efforts.

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Executive Summary

Children in King County are being referred to the Birth-3 Early Intervention Program at lower rates than expected for the population, and it is believed that some children are being referred too late. SOAR has a goal of assuring that children and families most in need of services receive high-quality, affordable and culturally competent services early. The SOAR Early Intervention Action Team believes that improving physician Early Intervention referrals will help support this goal. **The Medical Provider-Early Intervention Partnership Project** seeks to build partnerships with medical providers that encourage and facilitate their ability to successfully identify and refer families into early intervention services (birth to 3); and set the stage for wider implementation of successful partnerships throughout King County.

This report is informed by a series of interviews with Early Intervention Providers, Medical Providers, and other stakeholders relevant to the subject matter. In addition, a research review was conducted to help inform best practices. The EI Program has many strengths, most notably the passion of all the people involved in caring for children. This report focuses on areas for potential improvement, calling on the collective wisdom of those on the ground. The process generated a number of specific areas of concern about the current system as it relates to Early Intervention and physician referral. It also stimulated a series of ideas for how to improve the system, all aimed at enhancing access to services for children and families; and ultimately improving outcomes for children.

Early Intervention Provider Perspectives

Early Intervention providers believe some children are being referred too late, and describe a complex situation with incomplete data. They believe that some children are not being referred in a timely fashion, some are not deemed eligible for services once they are referred, some are being referred to services that are not included in the ITEIP data, some are being referred to the EI system after receiving services in a private setting, and some children are being served without having their data included in the ITEIP system. EI Providers believe that it is imperative that King County gain a true understanding of this situation as part of the overall strategy to improve referrals.

Early Intervention Providers believe that doctors can be good partners, and that doctors have a role in improving the EI referral process. Early Intervention providers have variable levels of interaction and communication with doctors around their services. While most EI Providers believe that direct outreach to doctors would facilitate information sharing, build relationships, and encourage referrals; few currently do this outreach; most often due to staffing restraints. Most EI Providers report communication with doctors around referral intake, evaluation, and IFSP reporting, but the process and frequency is inconsistent across programs.

EI providers believe that doctors need a better understanding of the EI system and how it works. Providers would like to see a collaborative approach to educating physicians, with some pieces being led centrally by King County; and others by EI Providers in direct face-to-face interactions with Medical Providers. EI Providers also recognize that their systems could more effectively communicate with

physicians throughout the process of an individual child's progression through the EI Program, and that procedures (like summary reports and other forms) might enhance relationships and future referrals.

While EI Providers believe the Program provides many needed services to families, they also recognize areas where system change could help them more effectively serve families, including: baseline referral data; ITEIP computer/data system issues; eligibility determination; service capacity; payment for services; staff training; program quality measurement and improvement; competition and collaboration; school district involvement; and system financing. EI Providers suggest methods for better assessing referral and service rates and improving data sources. They would like technical assistance around eligibility generally to assure consistency across programs; and specifically around young children and premature infants. They believe there is a need to document current and predicted capacity needs for the programs, and for the system as a whole. Anticipating and planning for the impact of increasing referrals is needed before significant effort to increase referrals are implemented.

Medical Provider Perspectives

Doctors also believe that that some children are being referred too late to the Early Intervention Program. They believe they are partly responsible for late referrals, and that they have a role in improving the process. Most doctors and clinics refer families to the Early Intervention Program, but doctors do not understand the Early Intervention Program well. Specifically, doctors are not familiar with the role of FRCs/Family Resources Coordinators or with Individualized Family Service Plans (IFSPs). Doctors and clinics make referrals to the Early Intervention Program in a variety of ways, and many do not know about the central referral option, or what procedures the Program would prefer.

Once doctors do refer to the EI Program, they receive insufficient follow-up and information exchange about the child and family. Doctors want to know if their patients make an appointment, and to see the evaluation results. They want to know what services are recommended, and if the family participates. Doctors see families with difficulty following through, and believe that further information sharing with the EI Program would help increase the likelihood that families can complete the process. Doctors are interested in further information and resources about the Early Intervention Program. In general they do not feel they know how well the Program currently works.

Doctors are interested in educational efforts which increase their understanding and awareness of the program, how it works, and what they should expect. While many would welcome access to written and electronic information, they believe they would benefit most from in person "in services" by the EI Program in their offices. Doctors also believe that the system is overly complex and difficult to access, and that system changes may be needed to assure effective referral and evaluation processes and high quality services. Many see a huge need for direct support to families throughout the process, a case management approach which walks the families through the process from start to finish.

Washington State Opportunities

The Early Intervention Program and efforts to engage physicians more effectively with it have considerable opportunities to engage with other relevant efforts in Washington state. Doing so will

allow the EI Program to leverage existing interest in young children and strategies to improve outcomes. The momentum around Early Learning and the Kids Matter framework offer opportunities to see connections between systems, and to define strategies around desired outcomes being used across the state. The Washington State Medical Home Leadership Network has connections with physicians, extensive knowledge about this subject area, and an interest in the same outcomes. The Washington State Pediatric Learning Collaboratives have specifically implemented Quality Improvement strategies around developmental screening, and may have future opportunities to do so. Kids Get Care and the King County Children's Health Initiative efforts to increase children's access to high quality care, including developmental screening and services, provide both relevant experience and potential future opportunities for direct partnerships to implement strategies within King County. Finally, the Washington State Child Health Care Act provides very direct policy and funding opportunities around medical home and developmental screening. King County would be wise to build partnerships with these efforts to help facilitate more comprehensive strategies, and potentially tap into other funding sources and opportunities to leverage policy and positive outcomes in a systemic way.

Review of the Literature: Developmental Services and Systems Change

Despite the challenges, primary care physicians have a significant role to play around child development, particularly given their ready access to most young children. Unfortunately, the typical primary care physician approach to developmental surveillance is not identifying children early enough, and there are many practice barriers to change, including lack of continuity, time constraints, and reimbursement issues. Developmental services in doctors' practices can be described as encompassing four areas: Assessment-to identify developmental risks and problems, Education for parents on child development and promoting learning, Intervention for developmental concerns, and Coordination of needed services.

From a developmental perspective, doctors are generally not as well-trained in child development as they would like to be, including lack of comfort with standardized developmental screening tools. Pediatric practice guidelines only recently began recommending formal developmental screening. There is broad recognition that education and quality improvement support is needed in order for doctors to embrace needed change around developmental services. States are working with physicians to improve the quality of children's health care. There is growing recognition that improving the quality of children's health care, including developmental services, is a complex, multi-systems change process. States are also working with physicians to promote children's healthy mental development; demonstrating that standardized screening tools can help ensure healthy development; that screening must be accompanied by access to follow up services; and that project demonstrations can inspire and test policy change. Strategies for improving the quality of preventive health care and developmental services make similar recommendations. Emphasis is placed on facilitating linkages between parts of the system, not just the referral itself. Overall, the literature affirms the complexity of the pieces of developmental services, including referrals. It demonstrates how the EI System should be integrated and connected with health care systems and community supports for families; with quality improvement strategies within each, and with needed policy changes.

Recommendations

The following recommendations are based on needs identified by stakeholders, most of which were expressed by early intervention providers, medical providers, and other stakeholders alike. They are also consistent with the findings noted in the research review section. The following potential strategies are not listed in a particular order. How many of these to initiate, and in what order, will need to be determined by the SOAR Early Intervention Action team and its partners. Choices will necessarily be made based on a combination of prioritization, feasibility, potential impact, and cost considerations. The goal is to provide a menu of possible next steps which are likely to be effective and embraced by those whom they impact; and to build from the strengths of the system and potential partners.

Early Intervention and Medical Provider Strategies

- Implement a plan to educate primary care Medical Providers about the Early Intervention Program
- Implement a plan to educate hospitals and NICU programs about the EI Program
- Implement a plan to improve and systemize communication between Early Intervention Providers and Medical Providers at key touch points
- Support EI Providers with technical assistance
- Support training for primary care providers to help them implement practice-based systems change for developmental care
- Identify and promote key policy changes

Systems Level Strategies

- Determine goals within the Early Intervention system through strategic partnership efforts
- Collect King County data to help inform all strategies, such as capacity, referral and private service data
- Help monitor and determine appropriateness of referrals
- Plan for a response to increased referrals, and monitoring of impact
- Leverage medical home and early learning efforts
- Recognize the larger systems issues and context of the Early Intervention Program within Early Childhood Systems

Project Overview

The following information describes the Medical Provider-Early Intervention Partnership Project as envisioned prior to embarking on the interviews informing this report. It includes a number of working assumptions which were acknowledged at the outset; but open to challenge through the process.

SOAR Goal: Children and families most in need of services receive high-quality, affordable and culturally competent services early.

Problem Statement: Children in King County are not being referred early enough to the Birth-3 Early intervention programs.

(Part of the) Solution: Improve the Early Intervention referral timing/rate by physicians.

Project Overview: The project will build partnerships with medical providers that encourage and facilitate their ability to successfully identify and refer families into early intervention services (birth to 3); and set the stage for wider implementation of successful partnerships throughout King County.

***Why?** Pediatric medical providers are uniquely positioned to facilitate early intervention because they 1) interact regularly with families from birth (or before); 2) are trained to monitor and promote child development through regular preventive visits with children and parents; and 3) are often seen as trusted messengers by families.*

Project Objectives

- I. Understand status of work-to-date around Early Intervention-Medical Provider Partnerships in King County
- II. Understand the challenges, opportunities, and services of Medical and Early Intervention Providers and Systems
- III. Understand status of work-to-date around Early Intervention - Medical Provider Partnerships in Washington State
- IV. Identify potential tools or processes to overcome identified barriers in King County (from King, other county, state, or national resources)

End product: A report which summarizes the above findings and presents a potential plan to pilot and implement strategies which will facilitate physician referrals to Early Intervention, helping to improve the overall timing of referrals. It is anticipated that this report will be used to shape future plans and requests for funding for SOAR priorities in this area.

Timeline: Fall 2007; report due in January 2008.

SOAR is a community collaborative focused on the success of children and youth, ages birth to eighteen, in King County. It is governed by a partnership council of stakeholders and leaders from local organizations, government, businesses and community coalitions. Information about SOAR's Prevention and Early Intervention Action Team can be found at:

http://www.childrenandyouth.org/actionteams_earlychildhood.html

Working Assumptions

Assumptions about the Overall Project

- There is widespread agreement that doctors are key players in improving children's access to early intervention. However, current practice around physician identification and referral of children to early intervention falls short of what research, policy, and practice protocols recommend
- The process of practice change is neither simple, nor quickly implemented
- Feasible and effective strategies are possible
- Systemic change- which starts from implementing feasible pilots which can be replicated- is needed to achieve desired goals at the community, county, or state level
- This project is part of "Early Childhood Systems," Early Learning, School Readiness, and Medical Home work
- There is existing information and expertise and specific work that should inform this project. There are also substantial strengths to be acknowledged and leveraged, in King County; in Washington state, and nationally
- The project will work with a subset of the community, aiming to leverage input strategically and realistically. For example, by doing thoughtful, but not exhaustive, needs assessments; such as focused interviews with practitioners serving large numbers of at-risk children; rather than a county wide written survey of all pediatric providers
- Understanding the needs of the two key partner groups (Medical and Early Intervention providers/systems) AND building effective cross-discipline relationships between them, are both vital to the project's success
- The objectives outlined, and the progress on this project, are not necessarily linear. Progress can be made on multiple goals simultaneously. For example a conversation with Medical Providers about current challenges or information needs (Objective II) may also touch on potential solutions to address the identified issues; and thus help inform Objectives IV.

Assumptions about Medical Providers

- Want to provide good care, and desire positive outcomes for children and families
- Have information needs around early intervention system and how to connect families
- Have barriers within their practices which make early identification and referrals challenging
- Lack relationships with the EI system which would facilitate improved practices around EI

Assumptions about Early Intervention systems/providers

- Want to provide effective services, and desire positive outcomes for children and families
- Have gaps in knowledge about medical system processes and barriers for providers
- Have barriers within EI systems to effective partnerships with medical providers
- Lack relationships with medical providers which would facilitate improved referral processes

Language and Terminology

Like most fields, the world of Early Intervention is full of terms and abbreviations which the average reader may not find familiar. A few phrases used in this report are described below. Please note that early intervention in other contexts can refer to services for older children, or even adults.

Birth to 3 or 0-3: Because the federal legislation, and associated state programs, refers only to children from birth to age 3 years, these services are sometimes referred to as “Birth to 3” services; or the centers which provide services as “Birth to 3” Centers.

Early Intervention Program: This is the term which King County uses in its new parent brochure to describe the Birth-3 Early Intervention system in King County. It will be used throughout the report.

Early Intervention Provider: Someone who provides services to children and families within the EI Program, such as a therapist, FRC, or a center.

Family Resources Coordinator (FRC): This individual is part of the Early Intervention Program, working closely with each family throughout the process of developmental evaluation and service planning and implementation. He/she helps to coordinate all the resources the family may need.

Individualized Family Service Plan (IFSP): This is the plan which outlines the goals and services to be provided for an individual child and family receiving Birth-3 Early Intervention services. An IFSP is created by the Early Intervention Program and the family, after a child is found eligible to receive Birth-3 Early Intervention services.

The Infant Toddler Early Intervention Program (ITEIP): This is the name Washington State has given to its early intervention program for children from birth up to age 3 years.

Medical Home: describes the provision of high quality primary care that is family-centered, comprehensive, coordinated, and culturally relevant; a regular place and person with whom a child and family have an ongoing relationship.

Medical provider: This is a professional licensed to provide pediatric health care to children. These are most commonly physicians (pediatricians and family practitioners) and nurse practitioners.

Part C: This is part of federal IDEA legislation which authorizes and funds early intervention services, providing both funding and regulations to the states. Some people refer to early intervention services which families receive as “Part C services.” Others refer to the federal money which helps pay for these services as “Part C dollars.”

Primary Care Provider – a medical provider who provides regular health care to children, including preventive (well child care) and care for acute and chronic illnesses.

In order to simplify the report, an attempt was made to use one term consistently when synonyms exist. Because doctors were the medical providers informing interviews, the term doctor or physician is often used as a shortcut; but statements are usually relevant for all medical providers.

Early Intervention Program Introduction

Introduction

In order to inform this section, interviews were held with program leadership at both the state and county levels in addition to brief reviews of websites and written materials.

Purpose

This section of the report is intended to be a very brief introduction to the systems which ultimately help support, direct, and regulate the Early Intervention Program in King County. A full review of these administrative agencies and their programs is beyond the scope of this report. The intent was to get their input into the information process which would take place for this project; and to welcome their input on the needs and potential strategies to improve the Early Intervention Program- Medical Provider relationship.

Federal IDEA Legislation Created Early Intervention Programs

The United States Congress established the Individuals with Disabilities Education Act (IDEA) Part C program in 1986 in recognition of "an urgent and substantial need" to:

- enhance the development of infants and toddlers with disabilities
- reduce educational costs by minimizing the need for special education through early intervention
- minimize the likelihood of institutionalization, and maximize independent living
- enhance the capacity of families to meet their child's needs

The Infant Toddler Early Intervention Program in Washington State

States are required to abide by IDEA Part C regulations, and mandated to provide services to all who are eligible. In the state of Washington, *"all children, birth to three, including children at risk for developmental delays, are entitled to participate in the following components with the consent of their parent(s): early identification, multidisciplinary evaluation, and determination of eligibility for early intervention services."* (Infant Toddler Early Intervention Program)

The state ITEIP program has long been interested in improving referral rates from physicians to the program. The staff recognizes the complexity of both the problem and efforts to address it. ITEIP wants families to be fully informed about the program, what it offers, and how it works; and recognizes that doctors can and should be part of the process of educating and connecting families. Outreach to providers and public awareness at the community level is mainly the responsibility of the local lead agencies. ITEIP sends an annual letter to medical providers explaining the program, and the referral process they can use to connect families with the IE Program. The state ITEIP program gets about 20 calls per month asking about the program, and refers those calls to the appropriate local agency. At the state level, there is an impression that physicians often do not get follow up on their referrals, and that this might be undermining efforts to enhance referral rates from doctors. Some of this may be related to

concerns over confidentiality and consent issues around sharing information between providers. There is also a concern that low rates of referrals in the first year of life are related to the lack of program participation, or referrals, by some hospitals in the state. Because hospitals do not provide services in natural environments, then can no longer be part of the Early Intervention Program. If hospitals continue to provide services and do not refer families to the IE system, it would contribute to either a complete lack of referrals, or late referrals, to the system.

The state ITEIP program is accountable to the federal government, Office of Special Education Programs. There are annual reporting requirements and a score card; including 14 indicators. Washington state has set annual performance targets for each indicator, and is monitoring progress toward them. According to data from the ITEIP State Performance Plan: Performance Targets and Actual Performance Scorecard, the state has relatively low numbers on 2 indicators relevant to this report. Indicator 5 is the percent of infants and toddlers birth to 1 with IFSPs compared to other states with similar eligibility definitions. Other states average 1.12%. Washington state is substantially lower, at 0.52% as of 12/06. This number reflects minimal change since the 12/04 baseline of 0.51%; and no real progress toward the performance targets for 12/05 (0.61%) and 12/06 (0.70%). Washington state is also behind comparable states for Indicator 6, the percent of infants and toddlers birth to 3 with IFSPs. Other states with similar eligibility definitions have rates of 2.61%, compared to Washington's 12/06 status of 1.8%. The good news is that, unlike rates for children under 1, Washington has made progress for children 0-3 as a group; exceeding the performance targets for 12/05 of 1.7%, and meeting the 12/06 Target of 1.80%. The ITEIP program is concerned about these service numbers, particularly those for children under 1 year of age; because they imply Washington is not serving as many children as estimates suggest are eligible; and because we are not meeting all our federal compliance targets.

Beginning in July 2007, the state has a new and different level of accountability, requiring the measurement of child and family outcomes. ITEIP has been working with SRI International (an independent, non-profit research institute), to develop the plan required by the federal government. These new reporting requirements are expected to add substantially to the workload of the IE Program, and its providers.

The King County Early Intervention Program

The state ITEIP program contracts its funds to a local lead agency within each county. In King County, this is the Developmental Disabilities Division (DDD) within the County Department of Community and Human Services. King County DDD then contracts with Early Intervention Providers and with a lead Family Resources Coordinator to provide services to families. King County DDD is engaged closely with the EI Providers, and with county level efforts to improve services to families. Jan Wrathall, the Program Manager, also chairs the SOAR Prevention and Early Intervention Action Team, which requested this report. The county program is very interested in improving rates of referral, and working more effectively with physicians. The county is also accountable to the state ITEIP program to demonstrate progress on the Performance Targets noted in the previous section. Similar to the state overall, King County is not making adequate progress on referrals of children under the age of 1.

At the county level there is a perception that under-referring is occurring at times among doctors, hospitals and previous EI contractors. There is a sense that the move to natural environments has been very divisive, and in some cases may be affecting referral patterns and practices. There is some evidence from other places that a 'single point of entry' – such as one referral number for everyone- helps increase referrals. However, in King County overall the provider network has not been supportive of that idea, and seems to prefer a blended model, with both a central number, and the option to refer directly to centers. DDD has recently restructured outreach activities, including the hiring of new staff. A centrally led countywide outreach process is currently being developed around the 800#. The staff also believes that increasing referrals among the youngest children will likely require outreach to hospitals and birthing centers. This might involve including information in hospital discharge packets; or providing staffing on site or as part of team; as has been done effectively in other counties like Spokane. Funding issues continue to be a significant challenge. King County has always made a priority of the Early Intervention Program, braiding funding locally to run the system, and adding County dollars. They are currently underfunded for the services provided in King County. Especially if outreach efforts to increase referrals are successful, funding will be an increasingly difficult issue.

Medical Providers and Family Rights

Families have certain legal rights provided to them around Early Intervention Services. Primary care medical providers are mandated to be aware of these rights, and to help families access them. Despite this, there is a sense by state and county EI programs that medical providers are not aware of this, and do not currently follow these regulations in many cases. *The following information is taken directly from the mailing that ITEIP sends to all licensed medical provider.* (Infant Toddler Early Intervention Program)

Federal and state legislation assert that parents have a right to be referred for early intervention services if there is an established or suspected delay in their child's development. The intent is that every family who might need services has information about the availability of programs and that referrals be made in a timely manner.

Washington State requirements for the ITEIP state that individuals, such as primary care providers, who are in a position to make early intervention referrals shall:

- Refer families to an FRC within two working days of identifying a developmental delay or a disability that could lead to a delay, unless a family requests an extension to the timeline or requests that a referral not be made;
- Explain the services available to families when they accept a referral to an FRC (including screening, evaluation, service coordination, an IFSP, and the potential for special funding);
- Inform parents that the referral does not commit them to participate in the early intervention program;
- Maintain written documentation of the parent's permission to refer, the parent's request that a referral not be made, or the parent's request to extend the 2-day referral timeline.

Therefore primary care providers are asked to:

- Attend to developmental milestones
- Ask parents about their children's development and
- Respond to parents' concerns.

The Perspectives of Early Intervention Providers

Introduction

In order to inform this section, a series of extensive interviews was held with four of the King County EI contract providers, and with the lead FRC for King County. The other contract EI providers were all offered the opportunity to provide input via email or an interview. Information was also obtained from the author's attendance at a meeting of the EI Prevention Action Team who had helped conceive this project; and from a local hospital which employs therapists who serve children under the age of 3.

Purpose

This section of the report is designed to better understand how the Early Intervention Program works from the perspective of those providing EI services. An attempt was made to understand and summarize how families access their services, how EI providers interact with physicians, and how EI providers believe the system is working overall. Providers were asked to suggest ideas to improve systems, particularly around doctor referral patterns.

Findings

Overview of the Early Intervention Program: From referral to an individualized plan

While each King County EI provider is unique, the overall process for what happens when a child/family is referred is relatively consistent. This overview is not a description of the legal or regulatory requirements of the process, but rather an attempt to describe 'what actually happens' to a family, based on interviews with a number of EI providers in King County. The steps include: referral intake; information gathering; comprehensive developmental evaluation; and eligibility determination. If a child is eligible, then the process continues with creation of an IFSP; provision of EI services; and monitoring and IFSP updates.

Referral intake: The initial referral can start at King County's central point of entry, at 1-800-756-5437, or directly at an Early Intervention center. Currently approximately 25-30% of referrals are initiated through the central 800#. When a referral is received (typically from a family or a doctor), an intake process begins. Often done initially by phone, the EI Program typically obtains basic demographic information (such as name, age, and contact information), the reason for referral, and insurance information. Families learn about the role of a Family Resources Coordinator, and are usually introduced to one fairly early on in the process. In some cases, an FRC may do the initial intake.

Information gathering: More in-depth information is subsequently gathered from the family. This might occur by phone, in the family's home, or in the center; and this might be part of the full evaluation, or happen as a separate step. EI providers try to gather any previous child development evaluation information and relevant medical or other data about the child. EI providers explain the EI Program to families, including explaining their legal rights.

Comprehensive developmental evaluation: Once the family has received information about the process, and has agreed to proceed, an evaluation is scheduled. EI providers are required to do a comprehensive developmental evaluation. One provider described “*five required areas -communication (receptive and expressive); motor (fine and gross); cognitive; social; and adaptive.*” Evaluations take place either at a center, or in the family’s home, typically by at least two trained providers, and can take between 1-3 hours to complete. Regulations require the use of standardized screening tools, but providers report there is a large number of possible choices, and so evaluations can be tailored to the individual situation.

Eligibility determination: There are specific eligibility requirements for the EI Program, which typically involve the presence of developmental delays which meet specific criteria for the amount delay. Many times, it is obvious at the time of the assessment whether or not the child will qualify for services. If that is the case, the family is usually notified of the findings verbally at that time of the evaluation. Subsequently, a full evaluation report is generated, and this is usually shared with both the family and the child’s doctor. If a child is deemed eligible, a recommendation is made to the family to schedule the IFSP meeting. It is important to note that children who do not meet eligibility criteria may have real developmental issues. Therefore a determination that a child “does not qualify” is not the same thing as saying “there are no concerns that need following.” Some families, ideally in consultation with their child’s doctor, may decide that it is in their child’s best interest to pursue intervention services for identified issues, even though they do not currently meet the criteria required for the EI Program. Children can also be referred for re-evaluation (at least) 6 months after the initial one; and some children are found eligible after the second evaluation.

Creation of an IFSP: In the EI Program, all services are provided under the auspices of an Individualized Family Service Plan, or IFSP. While these plans can in some ways be seen as analogous to the IEPs (Individualized Educational Programs) created within public special education program for children 3 years and older; IFSP’s are not exactly the same. They differ most significantly in that they are a family plan, not just a plan for the child; and that they are to take place in the community in “natural environments,” rather than in the school setting more typical for an IEP. Following the child’s developmental evaluation, a meeting is held to review the evaluation findings, define goals, and outline a plan for services to help the family and child progress toward those goals. Typically the process starts with a group meeting, which includes the family, a Family Resources Coordinator, and relevant early intervention providers, which might include, for example, physical therapists, occupational therapists, speech and language therapists, and teachers. Families are welcome to include other individuals relevant to the child’s situation, such as child care providers and other family members. While EI providers typically would welcome doctor involvement in IFSP meetings, participation is relatively rare given practical scheduling issues, and it is probably unusual for the child’s doctor to be invited directly.

Provision of Early Intervention services: Once the team and the family have completed and agreed to an IFSP, the service plan outlined therein is implemented. Most commonly now services will occur in the family’s home. Federal, state and county regulations now require that children be served in “natural environments.” In the past, most services were provided in Early Intervention centers, but there has

been a gradual transition into new ways of service provision in response to regulations. EI providers report varied histories of these transitions, with some embracing it from the start, and others describing themselves as “kicking and screaming until the last minute!” The process through which each EI Provider brings services to families vary. Some describe using a primary service provider model, some a parent coach model, and some a multiple provider model. A review of the history and current status of the natural environment movement, and even its history within King County, is beyond the scope of this report. However, it is important for families and medical providers to understand that most children 0-3 will receive IE Program services within their homes.

Monitoring and IFSP updates: A child and family’s progress within the context of the IFSP is reviewed with the family at least every 6 months. At that time, goals may be updated or changed; and service plans can be revised as needed. Sometimes children’s needs evolve over time. For example, a provider described how a child may initially have primarily motor issues; and subsequently need more of an emphasis on speech and communication interventions. Children who remain eligible can continue to receive services until their third birthday. After that time, further needs must be evaluated and addressed through the IDEA “Part B” system, the school district affiliated programs which serve children with special educational needs starting at the age of 3 years.

Early Intervention contractors believe some children (0-3) are being referred too late, but describe a complex situation with incomplete data.

This project was started on the premise that overall children are being referred too late to the Early Intervention Program in King County. At first, this premise seems clear. There are Federal, State, and King County data showing that the percentage of children receiving early intervention services is lower than expected. These “expected” numbers to which King County is compared are based on population estimates for the prevalence of developmental delays, and are relatively well accepted across the country. In talking with EI providers, however, it became clear that the situation is not that simple. Therefore, before embarking on a discussion of ways to improve referral numbers, it is necessary to try to better understand what the referral situation really is.

Some EI providers take the numbers at face value, believing there is clearly a problem needing a solution; others are less sure the numbers tell the real story. The reported EI rates for King County are some of the worst in the state; and overall Washington isn’t doing well compared to national expectations. However, several EI providers reported that they do not think numbers for King County are entirely accurate, especially for the apparently “worst” numbers for children less than 1 year of age. EI providers do not believe all children are being counted in these numbers, which come from the ITEIP database; and therefore they are underestimates of the number of children being evaluated or receiving services for developmental issues. EI providers offer a number of reasons (below) that the rates could be low, or look like “late” referrals. EI providers believe all of these things have happened, or are happening. Therefore, EI providers believe that we do not have accurate, comprehensive County numbers describing when and where children are being referred, and how they are being served.

EI providers have theories for why referral numbers may be lower than desired

Providers offered suggestions about why referrals may be late, and did not assume that the issue mainly related to doctors. What follows are summaries of the ideas that EI providers felt need to be considered when creating a plan designed to increase referral rates.

Children are not being referred in a timely fashion (true late referrals)

Some EI providers definitely see children being referred too late for their services, particularly for speech issues. *“For speech – providers often wait until the child is 2.5 years; by then they can barely get services before turning 3, when they have to transition to another system.”* Some providers report that referral timing depends on the child’s issues. *“There are lots of private providers, especially for speech; kids with more global issues are more likely to get referred to us.”* Others report that children who do not have a regular doctor are more likely to come in late. *“We don’t see a lot of kids referred too late – and those that do usually did not have a Primary Care Provider (e.g. a regular doctor).”* Some providers report that the possibility of late referrals becomes more obvious when kids are seen in programs after age 3, something 0-3 programs would not see themselves. *“We see kids in programs for 3-5 year olds that seems like they should have been referred earlier.”* And, of course, if there are children who are never referred to a system until school age, early intervention providers would not know this directly; unless information is shared by the school districts or others serving older children.

Children are not deemed eligible for services once they are referred

After referral, children will only receive services from the EI Program if they qualify using program specific criteria for eligibility. While there are approved standardized tools for evaluation, there is flexibility in the system which may create some inconsistency across evaluators, or across programs, in terms of determining eligibility. Very young children in general will be harder to qualify because demonstrating a required “amount of delay” is more challenging earlier in child development. There may be some referred children who are appropriately evaluated as not eligible; there might be ‘missed’ kids who should qualify but do not on their initial evaluation; and there are likely children who would qualify if evaluated at a later age. *“With the tools we have and the qualification requirements it is difficult to qualify very young children- so we may be NOT qualifying some who might be qualified elsewhere. When young kids aren’t qualified, they can be re-evaluated again –but not for 6 months. Docs might not realize they can send them back (and by then it’ll be past 12 months of age).”* Determining eligibility for services is not a simple process. Many EI providers felt there was an ongoing need for, and interest in, technical assistance related to eligibility processes.

Children are being referred to services that are not included in the ITEIP data

Families’ use of “private” providers, e.g. those who are not IE contractors, seems to be the biggest issue that could significantly impact service rates. *“We think a lot of kids are being seen in private services – we really need to get those numbers to grasp the issue.”* In some communities, there are a lot of private providers, and many families that now have very comprehensive insurance, with no limits on visits, and no copays. When families perceive they are receiving good services, and there is no financial incentive to

look to another system, it makes sense they would stay with private providers. Medical providers often have established positive relationships with these providers, so it also makes sense they would refer to them. EI providers do not think that primary care doctors necessarily know the difference between referring a child to a private therapist vs. the EI Program. Many believe the private therapists, hospital-based therapists and physicians, and families lack this understanding as well. In other words, the referral patterns outside of the EI Program may often not be intentionally made “outside the system.” And, finally, EI providers believe their own system creates disincentives to collaborate. *“Part C won’t pay for ‘duplicated services.’ So if families being seen in private therapy came to EI, the private provider would lose the patient. This is a real disincentive for private providers to refer or partner with EI programs.”*

Children are being referred to the EI system after receiving services in a private setting

Families who are being seen by private providers as described earlier, but who do not have unlimited insurance, are often referred to EI after their insurance benefits run out. Therefore, if these are considered “original intakes,” as they likely would be the first time the child was put into the EI data system, they would appear to be “late” referrals. Sometimes children have received multiple services prior to referral, sometimes the care has been limited to a particular type of therapy. It is variable whether the child clearly needed more comprehensive services, or if the family felt they made good progress in the private system. Many families tell EI providers that they did not know about the EI Program, and that they wish they had known earlier. Most of the time children in this situation have a “gap” in their services because of the lag time between when their private services “run out” and the time it takes to get an evaluation, an IFSP, and a begin services within the EI Program.

Children are being served, but data is not included in the ITEIP system

Almost every EI provider interviewed described difficulties with the data system, and how “cumbersome” many find it. *“Not every kid who is referred is in there. At first, we only put those who qualify into the system; now we put in all that we evaluate.”* Since IE contractors must use the data system to receive payment for the children they serve, it seems unlikely that once children are truly “in” the EI Program they would not be included in the data system. However, children who are being evaluated and receiving services only outside of the IE Program (e.g. through private providers, as described above) are not included in the data system.

EI Providers believe that doctors can be good partners, and that doctors have a role in improving the EI referral process.

EI providers have many good things to say about doctors and connections with the EI system. One EI provider reports significant improvement over time in doctor referral patterns. *“We have great medical providers - 95% of our referrals are from doctors. In the past we did have lots of late referrals from doctors; but now it is rare to get late referrals.”* Another reports *“We get lots of referrals from doctors and clinics. We have a good relationship with doctors. We build and maintain it, and think doctors like to refer to people they know.”* Some EI providers report that hospitals are good referrers, others report that they rarely send patients to them.

EI providers do note variability in what doctors know and do, and some areas for potential improvement. *“Some doctors are used to a medical model, and referring to private therapists as needed; hospitals tend to refer to private therapists, too.”* Providers note patterns vary with children’s issues. *“I think doctors are not aware that there are effective services for kids 1-2 years old for speech. They are good at catching and referring motor issues early.”* Some medical providers seem less inclined to refer at all, *“There seems to be a ‘wait and see’ attitude.”*

Early Intervention providers have variable levels of interaction and communication with doctors around their services, both generally, and around specific children and families.

Outreach and education for doctors

All EI providers noted that doctors do not know enough about their systems, and that it would be better if doctors were more informed, and had stronger relationships with the programs. Some programs have done specific outreach in the past, some are doing it currently, and many would like to do more but believe they have no staff capacity to do so. Some programs report quite a bit of interaction with doctors by mail, and by the creation and use of referral forms. *“We used to do face to face, but haven’t in 1-1.5 years, but we ‘talk about’ doing it.” “We haven’t done much outreach to doctors, but we would like to if we had time.”* Across the county there have been “system” outreach efforts in the past via public health nurses, and by various clinic staff on how to make a referral. However, *“this needs to be done over and over, as there are staff transitions.”* King County DDD has recently hired a new Outreach Coordinator, so there will be new centralized plans for outreach and education.

One EI program described a very comprehensive and successful outreach effort to doctors over the past year. This includes personal visits to meet with doctors in their offices with EI Program staff and a therapist in attendance. The effort has created new forms for outreach and for doctor referrals; and a ‘leave-behind’ binder of information about the program and other community resources for doctors. All this information is shared in person. This has created positive relationships, with doctors now using the program for referrals, but also as a resource for them to call with questions about services for families. The program saw an increase in number of children being served by 67% in an 8 month period! It was so successful that outreach efforts needed to be modified, because service capacity was increasingly stressed by the increasing numbers of referrals.

Communication with doctors around referral intake

EI providers encourage referrals from doctors, and have a variety of ways for receiving them. Some programs have referral forms that they like doctors to use and fax in or send electronically; others take most of their referrals by phone or by a more generic prescription or fax. Some EI providers have found creating specific forms to be very helpful in ensuring they have the needed information to connect with the family, understand the concerns, and be able to access insurance coverage. However, all programs accept referrals however they come in, and then attempt to get the missing information they need via the family and the doctor’s office. Once a referral is received, programs complete intake with the family and schedule an evaluation. Some clinics let the doctor know they’ve connected with the family for intake, or to schedule an appointment; but it is typical for doctors not to hear back until after the

evaluation takes places. The central FRC number for King County does not directly let doctors know that families have called, or if their patients have been referred to an IE provider. When a family is referred by a doctor into the EI Program, and the family never connects with the program for further intake or to schedule an evaluation, it is quite likely that the referring doctor would never be notified.

Communication with doctors after evaluation

EI programs report that once a family completes intake and has an evaluation, they communicate with the referring doctor. Most programs report sending either a comprehensive evaluation report, or a summary document stating whether or not the child qualified for services. Once a child is qualified, and their IFSP is completed, many programs report that they communicate again with referring physicians. Some send a full IFSP report; others send a list of recommended services from the IFSP. Families working with the central FRC are asked if they want their IFSP report sent to their child's doctor. All providers noted that the IFSP report generated by the ITEIP system is extremely long, difficult to decipher, and unlikely to be helpful to most doctors. Despite this, some programs send it to the referring doctors, while others try to send a more streamlined summary created from it. However, there is no summary generated by the system, so EI Providers who do this must create their own template and devote the time to creating such a report. Many providers report that they don't have the time to create additional reports; but readily agree that a more streamlined summary would be a useful communication tool. As one noted *"We don't think a doctor would read the IFSP. We try to edit the IFSP form but it takes an insane amount of time to do this. We highlight it with families as we go through it with them."*

EI providers believe that doctors need a better understanding of the EI Program and how it works.

EI providers identify a number of issues which may be challenging to doctor referrals. They can essentially be summarized as *the need for doctors to understand the EI Program and how it works, and how they can effectively refer patients to it*. There is widespread agreement that most doctors do not understand the system, and that the EI system has not adequately educated providers about itself. *"There is a need to educate doctors countywide, and this isn't being done."* While the need for awareness around early intervention is a general issue, the programs have also been changing in response to federal, state and county regulations; and to national trends in best practices. Therefore even doctors who might have known about the system in the past are unlikely to understand how many current programs are run. The relatively recent transformation of the EI Program from a primarily clinic or site-based program, to a primarily home and community based program in "natural environments," is a huge change. Doctors need to know about this in order to understand what their patients will encounter, and to be able to support and encourage their participation when appropriate.

EI Providers noted some of the following specific educational needs for doctors. *"Doctors lack knowledge about the Early Intervention system as a whole, from referral, to evaluation, to service provision."* *"Doctors don't know the difference between the 0-3 'system' contractor and other therapy options."* Thus many doctors who currently refer to private services, or to the EI Program, may not know which they are referring to, or the difference between them. This may especially be true because some

King County providers previously were EI Program contractors; and continue to provide many services in the community. In addition to not knowing whether they are referring to a system of care; they are likely not informed about how services are provided. *“Doctors don’t know the ways services can be provided; including home services and the natural environment requirements; what a primary service provider model is, etc.”*

While most EI providers think the average doctor is not familiar with the details of the system, and therefore not making informed choices; some EI providers believe that there are philosophical difference driving referral patterns from some doctors, clinics, or hospitals. *“I see a divide between therapists in the hospital and in community. It is hard to switch to natural environments. There may be a philosophy divide; a lack of knowledge (or interest); a comfort with what they know. Some hospitals seem to keep patients ‘in house’ (for services) even if it is not convenient for the family.”* Some EI providers believe that frustrations with, or disagreements about, Federal, State or County regulations may be impacting some doctor’s inclination to refer to the EI Program; or if they do refer, what program they choose to refer to.

When it comes to doctors connecting families with the system, EI providers feel that many doctors do not understand the referral process and what is needed from them. One provider summed this up well. *“Programs need a prescription from doctors for the comprehensive evaluation that is mandated by federal law. Typically we receive a referral for only one area, like speech. Our referral person tries to get the comprehensive prescription that we need from the doctor, in order to get paid for our services; but they often say no. We need doctors to understand this.”*

EI Providers have ideas to encourage and support appropriate referrals from doctors

EI Providers would like doctors to better understand the system and how they can help families access it effectively. EI providers believe that the best outcome will come from a combination of county-wide/streamlined communications; and personal interactions between doctors and the EI programs. *“We would love a collaborative, county wide and program specific effort. We would like the county to educate docs in general about the referral process and the requirements –including 5 areas, in home services, etc.”*

EI providers want effective general outreach and education for doctors across the county, with the county, and all programs using similar messaging and materials. *“We need ONE SET of materials for doctors – the same binder everyone has/uses and gives out –with room to adjust and add some program specific materials.”* EI Providers know that doctor education is an ongoing need, not a onetime effort. *“Doctors need ongoing contact to keep up to date.”*

EI providers want to improve the referral process itself. Doctors need to know what is needed from them, and have a clear process for communicating with EI providers. *“Referral forms can help assure the right information gets to us, and helps with the initial conversation with the family.”* This will make processes more efficient, decrease staff time, and increase the chance that programs will be able to bill insurance for their services. Programs not currently using referral forms could consider adopting one; or

programs countywide could consider a common form, so doctors who refer to multiple sites would only need to have one on hand.

EI providers believe that communicating with doctors about individual patients is helpful. There is variability across programs currently around this, and all acknowledge challenges in doing so. They believe it would be helpful to routinely share information with doctors after evaluations, and after IFSP's are created. Many think that summary sheets of some kind might be a helpful tool for these communications. All acknowledge that doing so takes staff time that they may not have.

Programs that have done personal outreach believe it is effective and want to keep doing it; other programs want to emulate it. *"We could do in-services with doctors. At big clinics not all providers know about us, as some doctors refer and others don't."* Almost all providers noted that this personal connection and visits with doctors offices would be helpful, and they'd like to do it. Most, however, felt that they didn't currently have the staff capacity to do this; and that they don't have funding for this type of outreach. Programs doing outreach believe it is a worthwhile use of staff time; however staff and service capacity and funding seems to be variable across sites.

In terms of impacting the youngest referrals, many providers felt that outreach to birth hospitals and neonatal intensive care units (NICU's) would be useful, either personally by the programs, or county wide. There was fairly broad agreement that many of these settings are either not as aware as they could be of the EI Program, or are not actively referring to it as much as they could. The EI providers are not currently doing this type of outreach. However, they felt this was imperative if a significant goal to be addressed is the early referrals, less than one year of age, as many of these would be from premature infants, or those born with problems known to be associated with developmental delays.

EI Providers believe the EI Program provides many needed services to families

Despite the limitations expressed in this report, EI providers believe that the system is an important one for children and families. The main advantages of the formal EI system is that it provides a comprehensive evaluation, and for children who qualify, an Individualized Family Service Plan (IFSP) supported by a Family Resources Coordinator. The comprehensiveness of the evaluation and the services, and the care coordination, is rarely duplicated in any other setting. Families are also entitled to be served regardless of insurance or financial status. Therefore, the system should provide a way for all children with developmental delays to be referred, have a comprehensive evaluation, and to receive needed services in a family-centered way. Providers note that *"Once they are in the system, families are usually very happy."* While most EI providers receive direct referrals from doctors, they note that *"The central FRC is helpful when there is no doctor, or if it is a non-MD referral. If we are (temporarily) 'full' we will refer back to her. This has made a real difference for the system."*

EI Providers identify overall system challenges

EI Providers describe multiple areas that challenge both their current ability to provide effective services, and their potential capacity to serve more children if referrals were to increase. These issues are not specific to doctors, but impact the system overall. While further elucidating these in detail is

beyond the scope of this report, it is important to acknowledge their existence. Those interested in improving the EI Program, and specifically increasing doctor referrals, must realize that their actions in one part of the system will inevitably impact or be impacted by, many of these issues.

The information in this section is predominately gained from topics which spontaneously arose within the context of interviews, but were not the main target for information gathering. The financing issues, in particular, are very complex, and the explanation below is thought to be accurate as a brief overview. *However, anyone interested in understanding specific policies, laws, or funding methodologies should obtain further information from the appropriate regulations and involved agencies.*

ITEIP computer/data system: All providers noted that is time consuming and the output is hard to read. It negatively impacts their daily work of assessments and IFSPs; and their ability to communicate with others.

Determining eligibility: The Evaluation tools allowed are a huge list; but in general it is hard to qualify very young children. Programs are unsure they are all making the same decisions, and would like technical assistance around some aspects of the process.

Service capacity: Most programs reported that they are at or near capacity in terms of both evaluation and service provision, but this does not appear well-documented at program or countywide levels. Many programs report that they could not easily increase their capacity, as it would require increased staffing. Several expressed concern about a generally limited pool of potential staff which they could try to hire, even if they had funding to do so. In some places staff positions currently remain open and hard to fill.

Payment for services: While publications say that services are free to families, or that families will be served regardless of ability to pay; actually managing funding locally for a specific patient is a huge challenge. In reality, centers bill medical insurance. It is very difficult to get the whole agency and staff credentialed with all the insurance contracts; so centers can't always bill. "Part C" federal birth-to-3 dollars are considered the payer of last resort, and therefore EI Providers are required to first obtain any other sources of payment. Generally, programs seem to access 1) child's medical insurance, 2) public dollars (such as Developmental Disabilities funding), and then, 3) part C. Families are typically expected to pay co-pays as they would with a medical visit. Once families have reached the maximum family payment or deductible (or are unable to pay), programs wave co pays, or provide scholarships, in effect losing at least part of the billable payment for those services.

Staff training: Providing in home services is very different from working in a clinic setting for therapists, or a classroom setting for teachers. It is particularly a challenge for new therapists to start out in home environment by themselves. Programs which use a single provider as the main source of intervention need providers to have a broader understanding of child development than single therapy schools/training programs typically provide to their students and trainees. There is a need to cross train staff in all areas of development within schools; as well as to provide in-the-field mentoring. Increasing the capacity of the system through the use of well-trained providers will require significant investment

in provider training and education, and perhaps changes in educational systems; processes which cannot occur quickly on a large scale.

Program quality: There is a need to measure and understand this, and impressions about the quality of services may impact referral patterns and family choices. We do not currently have a system to assess the quality of services offered in the Early Intervention Program. Creating such a system is challenging, particularly with the provision of services in natural environments. It is very hard to monitor a service provider who is in a home setting by him/herself, when compared to earlier systems of multiple therapists providing services in one location. Programs need supervisory staff time to observe, monitor, and mentor. Programs need outside help and support to think about measuring quality, and to implement Quality Improvement efforts; and this should be in the context of developing a system for measuring and reporting quality.

Competition and collaboration: There are differences of opinion about whether there are “true catchment areas” for provision of services, e.g. automatic assignment to a particular EI Provider based on the family’s address. It is not clear if this is much of a concern by sites currently, but it is an area that should be open for discussion, as perceived competition for funding, or for referrals, could be detrimental to efforts to improve the system as a whole. There is also a significant need to acknowledge the fact that services for many young children are commonly provided in private settings. How can and should the IE Program address this reality? Are there ways to partner together, or must it continue to be seen as an “either or” situation? This, too, has the potential to undermine efforts to improve the system, and outcomes for children and families.

School district involvement: Participation in the EI Program for children under age 3 is a new area of child development evaluation and service provision for many school districts. EI Providers report that there is already substantial variability between districts contracting with EI Programs to provide services, in contracting processes and payment rates. There is potential for conflict and competition between EI providers wanting to work with school districts; and between providers and districts. This contracting variability may also impact the quality of services within and across districts. These issues should be addressed systemically and proactively now, as districts are all scheduled to participate by 2009. While it is hoped that the inclusion of school districts in 0-3 services will improve access for families; the scope of the change and inclusion of so many new partners and new relationships in the system will inevitably complicate the system to some degree, at least initially. Even assuming that all participants are well-intentioned, the transition is fraught with challenges, and in need of thoughtful implementation.

System financing: This is very complex. According to interviews, some of the complexity of the funding streams can be described as follows. One stream of funding is from “Part C” Federal Infant-Toddler Early Intervention money. This comes to Washington’s State Lead Agency, the Infant Toddler Early Intervention Program (ITEIP), which is housed with the Division of Developmental Disabilities (DDD) of the state Department of Social and Health Services (DSHS). Some of this federal- to-state money is then contracted out to the counties via a local Early Intervention Services Lead Agency. In King County, this is the Developmental Disabilities Division (DDD) of the King County Department of Community and Human Services. King County DDD in turn contracts with Early Intervention Providers (‘contract agencies’) who

provide the services described in this report. In addition to the federal EI funding described above, King County DDD also adds additional funding which come from the State Division of Developmental Disabilities. These two sources of funding are combined by King County DDD, and contracted out together to the EI contract providers. Part C Federal dollars are required to be the “payer of last resort,” as noted in the earlier section about payment for services.

EI providers offer general ideas to improve the system.

In the same way that interviewees spontaneously mentioned many system challenges outlined in the previous section, there were times when specific strategies were mentioned which might be address them. While what follows is not the comprehensive list that might be generated were these questions the subject of focus, implementing some of these suggestions could impact the system in ways which are relevant to strategies specifically involving medical providers.

Referral and service rates – improving data

- Gather referral data within EI programs beyond anecdotally. Are kids really being seen too late, or are they being seen elsewhere? Consider data collection over 2-3 months, such as: Were new kids getting services elsewhere previously or not? Who referred them? Does the referral seem “late” to the EI Provider?
- Count the children in private services: at least an informal head count from the bigger programs, such as Swedish, Valley, EEU; and known groups of private therapists, especially on the east side
- Figure out a way to partner with private providers. Perhaps somehow add FRC services to what they do to get at the comprehensive goal? (Although it was noted that it is a potential problem that they are not providing services in a natural environment)

Eligibility

- Provide technical assistance around eligibility in general. If eligibility is more stringent in one setting than another; outcomes will differ. If doctors’ thresholds for referrals are different, the number referred, and the number found eligible, will differ. The system needs consistent guidance for doctors about who/when to refer. Guidance is also need to programs on eligibility screening. Without it, the impact of new outreach efforts to improve numbers will be hard to interpret when superimposed on existing (likely) variations in eligibility decision-making.
- Provide technical assistance around eligibility for younger children. Providers report that it can be very hard to qualify very young children using the 25% delay standard. Providers are not sure how to use the “informed clinical opinion” option for eligibility, and would like input around what is appropriate, and how it is done. A system discussion about this would create consistency, and might increase the number of children found eligible.
- Provide technical assistance around evaluation of premature infants. Providers report that there is variable use of chronological (actual) vs. corrected (accounting for how early the child was born) ages. Creating a consistent approach to qualifying preemies would make changes in referrals and eligibility numbers more meaningful. This is particularly important if a substantial

goal relates to improving referrals in the first year of life; and if increasing outreach to neonatal intensive care units (NICUs) and birth hospitals occurs.

Capacity

- Try to document current capacity (for both evaluation and service provision) within each EI program, and across the county as a whole
- Anticipate needed additional capacity for evaluation and service provision, and the potential impact of increasing referrals
- Document current capacity and anticipate additional capacity needs for the central 800# and associated services if referrals increase
- Consider capacity needs as a system across the county. As noted by one provider, *“to date we have managed growth internally via board and fundraising. We haven’t thought about doing it ‘outside of ourselves.’ But we are fortunate and realize other programs might not be able to do this.”*

The Perspectives of Medical Providers

Introduction

In order to inform this section, a series of interviews was held with twelve primary care providers who care for children. The group included both pediatricians and family physicians. While no Nurse Practitioners were directly interviewed, many of these physicians practice alongside Nurse Practitioners. These doctors work in a variety of settings from public health, to community clinics, to private practice, to university based clinics; together serving a range of income levels and cultural groups. Several clinics serve a large proportion of non-English speaking families; many serve large Medicaid or underinsured populations. Geographic location included Bellevue, West Seattle, Kent-Des Moines, Federal Way, and several different parts of Seattle.

Purpose

This section of the report is designed to better understand how these pediatric medical providers interact with the Early Intervention Program. An attempt was made to summarize how physicians make referrals, how they interact with EI Providers, and how the medical providers believe the system is working overall. Providers were asked to suggest ideas to improve systems, particularly around the referral process.

Findings

Doctors think that some children are being referred too late to the Early Intervention Program

When asked, doctors believe that late referrals to the Early Intervention Program are a problem, with 75% (9) saying at least some children are being referred too late. Another 17% (2) reported *“not in my practice,”* but seemed to believe it was likely true in other situations. Only 1 respondent (8%) said no, believing that children are not being referred too late. Comments included

“This depends on the kids/families. If they come in regularly for well child check ups, we refer pretty quickly if we’re concerned”

“I think that for kids who are grossly (obviously) delayed we do OK with referrals. However, kids with more marginal delays, especially language, are more likely to be missed.”

“I think that the doctors in our clinic DO refer the kids that they pick up in a timely fashion. At the same time, I am sure that many are missed because of rushed visits and developmental screening being placed at a lower priority than immunizations and measuring height and weight. Specifically, we were in the process of rolling out the ASQ (a standardized developmental screening tool) organization-wide, with good adoption of it by our providers, when we went to an electronic medical record and at the same time, central scheduling and 15 minute visits for well-child checks. The ASQ went out the window in

favor of a quick checklist done by the MA, and even that doesn't always get done or reviewed by the doc. Also, we are not screening for early signs of autism."

"Yes. I think parents are reluctant to hear a diagnosis unless it is unequivocal - i.e. Down Syndrome – and then the coordination of the first visit seems to take at least six weeks."

Doctors believe they are partly responsible for late referrals, and that they have a role in improving the process

Doctors note many potential barriers to successful referrals, including actions by the doctor or clinic. Doctors acknowledge that provider awareness is a problem, and many believe the system is hard to understand and navigate. One doctor said, *"I think providers are confused by the system and need education and support around knowing where to refer."* The medical system itself can be a barrier as well. *"Part of the problem is that lots of kids don't have primary care providers. Patients who've come to us from big private group practices see their regular provider less often, and it varies who they see. This is increasingly an issue with more providers in a practice. A doctor who doesn't know them may miss a problem, or suggest they talk with their regular doctor the next time instead of making a referral. Then the child can get lost in the follow up, especially if the concern isn't shared from doctor to doctor, or isn't put in the chart notes."*

Doctors also note that child and family situation, personal choices, and system limitations all impact what happens after doctors make a referral. Doctors believe that they often make timely referrals, but then the family may not end up following through. Doctors note that some families are reluctant to have an evaluation. Families facing multiple challenges are less likely to follow through with a referral. Transient populations often are difficult to connect with agencies. Language barriers are significant; and interpreter availability can be rather limited beyond Spanish. Families with limited English are very hard to connect with the EI Program. Often doctors call to make the referral directly for the family. The intake person then calls the family back in its own language, but it can still be very difficult for the family to understand who's calling them, or why. Some doctors report challenges getting patients evaluated who have no financial resources or who are undocumented; agencies seem reluctant to see them. Once children do get an evaluation and receive recommendations for services; some doctors report that is fairly common for patients to not show, even when services are scheduled at their home! Often therapists can't reach families, so children don't actually get the services which were recommended. So the process can 'fall through' at many stages- initial referral, initial intake, evaluation, service planning, and service implementation.

Doctors report that children with special health care needs often provide additional challenges. There are many children referred to primary care with complex medical needs, for example children who were born early and spent time at the neonatal intensive care unit (NICU). It is often very hard to establish continuity of care for these families after discharge. A doctor shared this example: *"Twin premature infants with complications were born very early. They have had only one primary care doctor appointment since leaving the NICU. I've pursued family a lot, using a Public Health Nurse, outreach,*

scheduling appointments, and calling the family. The family says they go elsewhere for care, but when we check with that doctor, they haven't been seen. They no show for any appointments we schedule. The children are now almost 3 years old! It's hard to know what to do. Family needs are very complex, and they may not see early intervention, or even primary care, as a priority." Doctors report that even when they successfully get kids in to the EI Program; they don't necessarily get a diagnosis right away. Often families lack the financial resources or insurance needed to get specialty care, or testing/evaluation about the underlying problem causing the developmental delay. This can be frustrating to both the family and the doctor.

Doctors unequivocally said that they believe that doctors have a role in improving this situation. (100%, 12) Doctors said that *"Overall we have a role in doing better,"* and specifically, *"We have a role in referring."* One doctor noted the challenges and responsibilities around a complicated referral process. *"Doctors have the responsibility to follow up on the referrals or help families navigate a very complicated system. Doctors have to anticipate the families' reluctance to acknowledge a problem and especially recognize cultural and linguistic barriers."*

Most doctors and clinics refer families to the Early Intervention Program

Three out of 4 doctors report making referrals to Birth to 3 services (9 or 75%). Two others report referring young children to services, but not necessarily the B-3 system. Doctors described the following groups of children they refer: 1) former premature infants; 2) children with identified genetic or medical problem that might impact development; and 3) children picked up on well child exams who seem to have atypical development or are not developing as expected, including speech, motor or neurological abnormalities. Doctors' processes for picking up a "well" child with a potential delay typically included asking about parental concerns with general or semi-structured questions; using the screening questions/red flags found on the Medicaid well-child forms; using screening questions built into electronic medical records or other charting tools; and responding to parent concerns. While some described experience with formal developmental screening tools, none reported their regular use in their practice (although this question wasn't always explicitly asked). All believed they were more likely to pick up concerns when families had good continuity and follow up; e.g. were seen regularly for checkups by the same doctor.

Doctors do not understand the Early Intervention Program well

Doctors do not think that the physicians and staff in their clinics understand the EI Program well; with 33% saying flat out "No," and 67% describing partial understanding, or that the knowledge is variable within the clinic. For example, in settings with both family practice and pediatric providers, there is a perception that the pediatricians may be more aware of the system. In situations where clinics engage residents (doctors in training) there are challenges around training and retraining new doctors who come through. In some cases nurse practitioners have more practice continuity than physicians and they may have more knowledge about the system. Some clinics have social workers who are very

familiar with community systems, including EI Program services. Provider continuity in general is an issue, as one doctor pointed out, *“Unfortunately, because of an increasing rate of turnover and change in our organization, I think there could be several new providers who do not understand the birth-to-three system.”* In general, doctors did not feel they could reliably say what their colleagues’ level of knowledge or understanding is; while most readily admitted they don’t fully understand the system themselves.

Doctors are not familiar with the role of FRCs/Family Resources Coordinators

In general, doctors are not familiar with Family Resource Coordinators (FRCs). When asked to describe an FRC, 17%(2) confidently gave a reasonable description of the FRC role, another 25% (3) guessed at a fairly good description, 8% (1) had heard the term but didn’t know what it meant; and a full 50% (6) had no idea what an FRC is. Notably, only one doctor (8%) knew how to connect with an FRC.

Doctors are not familiar with Individualized Family Service Plans (IFSP)

The majority of doctors are not familiar with either the term, or the concept, of an IFSP; with 67% (8) saying they do not know what an IFSP is. Of the remainder, 8% (1) said they knew what it is, but had never seen one; 8% (1) guessed a reasonable definition, 8% (1) thought it was a report of some kind, and 8% (1) knew what the initials stand for, but not what it is.

Doctors and clinics make referrals to the Early Intervention Program in a variety of ways

Doctors and clinics have a number of different ways that referrals may get made, including giving the family information so they can call; writing or faxing referrals; and calling to introduce the family, who will then in turn be called back. Many doctors note they modify their approach to try to meet each family’s needs. For example, if the family is non-English speaking, most clinics will call for them, or otherwise arrange for language interpretation. The approach varies with the circumstances and timing. One doctor reported recently seeing a patient with a resident. *“The family had been referred to early intervention at 2 years. Now, the child is back in clinic at 2.75 years; and after looking at the chart and asking the family, we realized they had not made contact with Early Intervention. So we put the family on the phone in the office and made the connection right there.”* See Table 1 for more details about referrals.

Many referrals for the EI Program go into the ‘general’ referral process for the clinic, meaning they are treated similar to a referral to a medical specialist. *“All referrals in our clinic have to go into our electronic medical record as an order. This then goes to our onsite/internal referral person, who figures out the details, gets approval, and then calls the family to say it’s been OK’d with insurance. Usually these (birth to 3 referrals) would be “generic referrals” in the computer; where we type in the concern, and then the referral person figures out where the family should go.”*

Doctor perception of the efficacy of these referral processes varies. *“We do all of the above depending on the circumstances, we frequently have to use several approaches until the actual evaluation takes*

place. This is one of the reasons why many evaluations happen late, the process is complicated for families to navigate it.”

In addition to the process by which a referral is initiated, where doctors refer young children with developmental concerns is variable. Some use the central intake phone number; others refer directly to a EI Program center. Even more will refer some children directly to a specific type of therapy that they believe a child needs. Some refer to family support systems with which they were familiar, such as Maternity Support Services or infant case management. Medical provider understanding of whether they have actually connected a family with the EI Program was quite variable. The issue of what to do seems complex. One provider gave an example of a speech concern and the stepwise way they tend to address it *“First we do a referral to hearing evaluation; once have that result, then we need a different referral and process for speech. The evaluations are done in different places, by different processes. It is cumbersome, and takes time and work to assure all the steps happen.”* Another provider uses the EI Program, and says *“Any child that we refer for any concern, including behavioral, will get a comprehensive evaluation. If additional services are needed, they will ask us for additional referrals, which we always authorize*

Table 1: Ways that doctors refer families to the Early Intervention Program

Referral process	Ever used
Give the family a phone #	27% (3)
Call someone for the family to start a referral	36% (4)
Write out a written referral and give to the family	18% (2)
Write out a written referral and fax it/send it to someone	27% (3)
Provide case management/support to the family	0%
Refer families directly to a Birth-3 Center	36% (4)
Refer families directly to therapy services you think are needed (e.g. PT/OT/Speech)	54% (6)
Use regular medical referral system	18% (2)

“We refer families to 0-3 via the central # for King County. It mostly works well. About 30% of the time they do not connect with the family for some reason. It has been confusing to have the “name” of the line to call seem to keep changing.”

Doctors receive insufficient follow-up and information exchange after referrals to the Early Intervention Program

Doctors report inconsistent follow-up, or sharing of information, after they’ve referred a family to the EI Program. In general, doctors do not receive any notification about whether a family they referred scheduled or kept an appointment. This typically only occurs when a patient is scheduled for a particular service and doesn’t show for the appointment, most frequently with therapy appointments in a hospital setting. More commonly, doctors report *“I find out months later that my referral went nowhere, i.e. the family did not follow through and I did not devise a mechanism for reminders.”*

Communications from FRC's are rare, with two doctors reporting getting evaluation reports, but not being sure from whom they came. It is much more common for doctors to receive reports from therapists; over 90% (10/11) report receiving these. Two doctors (18%) report they occasionally get feedback from families about their EI Program experiences.

Doctors are interested in further information and resources about the Early Intervention Program

All doctors except one report wanting more information about the EI Program. The physician who said no felt that her colleagues needed it. A variety of types of information were desired, with some doctors wanting all of the following, some only parts. Almost half (54% or 6) wanted more information about how the Birth-3 system works. Information about how to make a referral was desired by 45% (5). Doctors also express an interest in receiving more information about what happened following a referral. Doctors would like a summary report of the initial assessment (36% or 4); copies of the child's IFSP (36% or 4); a summary report of recommended services (45% or 5); and updates from therapists and service providers (36% or 4). One doctor noted *"I would welcome more detailed information about the entire scope and limitations of their services."*

Doctors have variable impressions about how well the Early Intervention Program currently works

Several doctors felt unable to answer this question saying *"I am not sure"* or *"I don't have enough experience to judge"* or *"I don't know much about it."* One doctor was very candid in reply, *"We don't know enough about it. I'm embarrassed. I checked around, and unfortunately, I'm typical for our clinic."* Other doctors reported concerns about how well the system works. *"There is the perception of limited slots, sometimes there is difficulty with logistics of appointments, and communication could be smoother."* Others stated that the system is too complex, and is hard to navigate. Still others noted that quality is variable. *"The early intervention system is quite spotty. (Our area) happens to be a bright spot because of a great center and also a pro-active school system interested in reaching every eligible child as soon as they turn 3. No such luck if you live (in a neighboring region)."* One doctor noted that the system seems to work well for her. She believes this is because she has a good relationship with the programs she uses, and has been in the community a long time. She also suspects she has more time with patients than many practices; so more time to think about child development. She does note that she has much more of a challenge once kids exit the EI Program; as school districts seem to have a higher threshold for services, and are far less user-friendly to doctors or families.

Doctors have challenges related to all kinds of referrals for children. *"Even Head Start referrals – which seem like they should be simple- are hard. We don't know where to send families; there is no single # to get to the program information for the family."* Doctors are interested in knowing how to do a better job around EI Program referrals, but they have a broader need for connecting families to community services. They typically feel under informed and unable to keep up with what resources are available, and how to help families access them.

Doctors have ideas to make it easier for them to refer families to the Early Intervention Program

Doctors recognize many potential needs for training and systems change. This section reflects a few of the spontaneous ideas suggested by physicians in the course of their interview. The needs are large, varied, and ongoing.

"In this state, where there are so many Family Practitioners, we have done a (fairly) good job of reaching pediatricians, but have not gotten the message out to all the Family Practitioners and mid-levels." (There is usually) no time to teach in an organized fashion within my organization. Also, this education needs to be ongoing, because good practice is changing, for example, new ways to screen for autism."

Doctor awareness and training

Doctors believe that increasing provider awareness and knowledge is vital, and they had several suggestions for doing so. There was a strong belief that pediatricians, family doctors, and mid-level practitioners (like nurse practitioners) all need to learn about the resources and how they work. There were several requests for more information, particularly written or electronic versions which could be put in office data bases, links to downloadable PDF's, etc. One doctor emphasized having one website to find all the information. Several wanted electronic communications, but many are in "email overload" and felt e-messages would not be read by most. One doctor suggested that *"a major PR campaign needs to take place with mailings, emails, clinic visits, etc. to get it on the radar of primary care providers and clinics."* Several doctors suggested having someone visit their offices to conduct "in-services" to teach them; visiting the clinic or an all-clinic meeting with providers. As another noted *"there is nothing like hearing it in person."* The relationship building that could take place in a face-to-face encounter was also thought to be very valuable. One doctor suggested covering a topic in a larger setting as well, *"It'd be great to have a workshop at Children's (hospital) about autism-particularly given the new recommendations about screening that the American Academy of Pediatrics just released. The resources out there for serving kids with autism are "mysterious" to most providers."*

System change

There was a common theme that the system is too complex and difficult to navigate, for doctors and for families. For example, some doctors were aware of a central number to call for intake, others were not. One doctor stated, *"I think if doctors had a specific clearing house to refer patients – vs. individual local programs – perhaps the follow up would be more prompt."* Another doctor noted that *"We refer families to EI via the central # for King County. It mostly works well. About 30% of the time they do not connect with the family for some reason."* This doctor was happy with a single point of contact, yet felt it wasn't working for a significant portion of patients referred.

Case management

As demonstrated through many examples throughout this section, there are many reasons why a referral which is initiated doesn't get completed by a family. Doctors for the most part felt that there needed to be more assistance throughout the process for many families, typically involving some more

direct support and case management. The Kids Get Care program was noted as a very successful model that was funded and staffed for about two years. One nurse did case management for families in several primary care clinics serving children. It was extremely helpful. The nurse set up systems and did in-services for providers related to early childhood and to 'focus of concerns' for older kids in school. She taught how to do it, provided phone numbers to call; etc. It kept families moving through the process, and the providers informed.

One doctor suggested a model that would be useful for low-income parents who struggle to advocate for their kids. This model would have a nurse (or other provider) who could be the interface between the education system and clinic. In her clinic, they've had intermittent roles like this that have been helpful, but not a permanent system. It was suggested that this could be implemented in a larger clinic, or a person shared between clinics, perhaps do it regionally, e.g. 'someone from the central area.' She knows of an effective model like this where a nurse in another community has a ½ time position doing this interface with the schools; serving all the kids and providing case management as needed.

Washington State Opportunities

Introduction

In order to inform this section, a series of interviews was held with people involved in efforts which have impacted, or have the potential to impact, physicians and the Early Intervention Program. Related documents were also reviewed. The efforts include Early Learning and Kids Matter; the Medical Home Leadership Network; Washington State Pediatric Learning Collaboratives; Kids Get Care; the King County Children's Health Initiative; and the Child Health Act. Two of the individuals are pediatricians who work primarily in systems-changes efforts. The interviewees are not EI providers themselves, but they possess knowledge, experience, and relationships which can help inform any future strategies implemented in King County. While it was not possible to comprehensively review all the potential informants or programs fitting these criteria, an attempt was made to address active efforts most likely to be potential partners to support King County efforts in the near future.

Purpose

Within King County and across the state, there are many people, organizations, and efforts which are relevant to the topics in this report. Any future strategies implemented in King County will likely be most successful if they learn from, and collaboratively build upon, existing and prior efforts. This section of the report is therefore intended to describe efforts in Washington state related to systems and to physician primary care practice which might inform, or actively partner with, future efforts to improve physician practices around identification and referral of children with possible developmental delays. An attempt was made to understand and summarize these efforts, and describe the potential 'leverage points' for connections moving forward. Interviewees were offered the opportunity to make suggestions around the issues being addressed in this report, and some did so.

Early Learning and Kids Matter

Recent years have seen steadily increasing attention to the needs of young children and families under the umbrella term "early learning." In 2006, a new Washington state cabinet level agency called the Department of Early Learning was created to *"bring visibility and focus to early learning, along with the capacity to partner with the private sector to develop improved early learning opportunities for children and their parents."* (Department of Early Learning) The new Department brought together the Division of Child Care and Early Learning, the Early Childhood Education and Assistance Program (ECEAP), and the Early Reading First program. Simultaneously in 2006, public and private funding partners joined to create Thrive by Five Washington, a non-profit organization. Thrive by Five Washington, its partners, and its grantees work to promote community-based, market-driven solutions that will expand access to early learning opportunities for all our state's children. Thrive by Five Washington will provide support and information to parents and caregivers while working to ensure that all children from birth to age five have access to excellent, affordable early learning, whether at home with a parent or caregiver, in child care, or in a preschool. Governor Gregoire co-chairs the Board of Thrive By Five Washington. (Thrive By Five Washington)

While fully reviewing the history and status of early learning efforts in Washington state is beyond the scope of this report, it is important to note that this issue is currently a high priority for Governor Gregoire, the state legislature, many state agencies, and high profile leaders in the business and philanthropic sectors. The importance of early learning is based on research demonstrating the science of early brain development, the capacities of very young children, and the importance of nurturing relationships and high quality early experiences to support optimal development for children (REF N2N). Public policy and private sector interests increasingly understand the data demonstrating significant economic returns received by both individuals and society when investments are made to support the needs of young children. Advocacy efforts around early learning public policy and program investments in Washington state are increasingly engaging diverse champions for children, including law enforcement, physicians, business leaders, and philanthropists. (Docs For Tots Washington State) (Fight Crime Invest in Kids Washington)

While the creation of the Department of Early Learning and Thrive By Five Washington were incredible milestones, they build upon a long history of advocacy for the needs of young children. They also build on an increasing focus on school readiness in the context of early childhood systems, as described in *Kids Matter*. (*Kids Matter: Improving Outcomes for Children in Washington State*, 2005). Kids Matter is a Washington state early childhood systems building framework which is informing many early childhood efforts, and is therefore relevant to this report. The Kids Matter Executive Summary is the source document most relevant for review by King County stakeholders; and the recently developed “Introduction to Kids Matter for early Learning Communities” is a companion document to help communities understand and use Kids Matter. (Sells, 2007) Where descriptions from Kids Matter below are in quotations, the text was drawn directly from this second document, with permission.

“Kids Matter is a collaborative and comprehensive strategic framework for building the early childhood system in Washington State in order to improve outcomes for children. Kids Matter offers a framework that supports the efforts of local and state stakeholders to coordinate, collaborate and integrate efforts that will lead to children being healthy and ready for school. Kids Matter identifies specific achievable outcomes within four goal areas: access to health insurance and medical homes; mental health and social-emotional development; early care and education/child care; and parenting information and support. Cutting across and integrated within each of these is a family support approach to achieving outcomes within the four goal areas.”

“Kids Matter is based on the premise that a statewide early childhood system (or “system of systems”) that is integrated, accessible, and supported by policies and financing is essential to children’s health and school readiness. It will take considerable “systems work” to move from our current fragmented systems of services, to an overall system that works more effectively for families.” Efforts to improve systems are conceptualized by Kids Matter as two different but inter-related processes: ‘Systems Organizing’ and ‘Service Capacity Building’ efforts. Because improving children’s connections with the Early Intervention Program also needs attention in both of these areas, the concepts may be helpful to review. “Systems Organizing efforts are those which facilitate collaborative and integrated system planning, implementation and evaluation. Currently, many public and private systems and services are

not designed to work effectively with each other. The goal is to facilitate development of a statewide integrated, early childhood system of systems; so that the parts of the system work well together from a child and family perspective. Service Capacity Building efforts are those which build the capacity of an effective early childhood system which includes the four goal areas of Kids Matter (health insurance/medical home; social-emotional/mental health; early care and education/child care; parenting information and support). Currently, there is insufficient capacity to meet the needs of families for high quality services in many of these areas. The goal is to facilitate capacity building of services within the early childhood system of systems; so that the services families want and need are accessible to them.” For more information about these two processes, see “An Introduction to Kids Matter.” (Sells, 2007)

In addition to the theoretical basis for finding Kids Matter useful, it is important to note there have been two Kids Matter Awareness and Utilization Surveys (Organizational Research Services, 2006) (Organizational Research Services, 2007). “These have confirmed broad awareness and familiarity with Kids Matter among early childhood stakeholders statewide. In 2007, 57% of the 470 respondents reported that the Kid Matter Framework had helped them to develop new or different relationships, partnerships or collaborations. Respondents also agree that the Kids Matter Framework will help organizations achieve positive outcomes for young children and their families. They also give many concrete examples of how they have, or plan to, use Kids Matter. The positive results of these surveys are important, because the more widespread its use, the more likely Kids Matter will be effective in facilitating the desired outcomes.”

“Kids Matter is an outcome-based, systems-change framework. Kids Matter is about changing systems in order to improve outcomes. Building from what science tells us, stakeholders collectively defined high-priority outcomes within each of the four goal areas. In keeping with the ‘systems’ approach, desired outcomes were defined in three levels within each goal area: System Changes, Parent and Caregiver Changes, and Child Changes. The ‘theory of change’ is that improving systems (system changes) will enhance parents’ and caregivers’ ability to meet children’s needs (parent and caregiver changes), and this will in turn improve outcomes for children (child changes). Collectively, these changes across all goal areas will help achieve the overall goal, that children are healthy and ready for school.”

“Kids Matter describes resource and policy needs. While the development of Kids Matter focused on defining outcomes, it recognized that key resources would be needed to implement effective strategies which would in turn improve outcomes. In addition to system-building initiatives and the many engaged partners and stakeholders needed to support change, Kids Matter defined three overarching resource need areas: Infrastructure, Communication, and Funding. In addition, stakeholders recognized that almost all potential strategies to implement Kids Matter would require the development, promotion and implementation of new policies.”

Within each of the Goal areas of Kids Matter, there are desired outcomes and strategies which are relevant to the Early Intervention Program. Table 2 demonstrates this, pulling out the desired outcomes most directly related to the goals of the Early Intervention Program, and/or related to physicians and

medical homes. A complete list of outcomes can be found the Kids Matter Executive Summary and the Introduction (REFS), but it is notable that about 75% of the Kids Matter outcomes are in this table! In other words, there are many places that EI Program goals are integral to the goals expressed in Kids Matter. As King County moves forward with strategies designed to improve physician referrals to the EI Program, or to enhance the EI Program overall, it may help facilitate planning to connect strategies with Kids Matter outcomes. Since communities across the state are using Kids Matter in their early learning efforts, and this is being encouraged by the Department of Early Learning, Thrive By Five and others, doing so may also make it easier for King County efforts to connect with and contribute to statewide efforts.

Table 2. Kids Matter Desired Outcomes Related to Physicians and Early Intervention Programs

Goal areas →	Health Insurance and Medical Home	Social, Emotional and Mental Health	Early Education and Child Care	Parenting information and support
Desired Outcomes				
System Changes	Increased number and percentage of children who have medical insurance	Increased availability of appropriate and coordinated mental health services for children	Increased ability for parents and caregivers to access community resources and support networks	Increased ability for parents and caregivers to access community resources and support networks
Parent/Caregiver Changes	Increased understanding of the importance of comprehensive health care Increased ability to recognize an emerging issue with their child's health or development and connect with appropriate services	Improved understanding and practice of nurturing behaviors to promote children's optimal social-emotional development and mental health *	Increased understanding of what children need for optimal health and development (<i>physical, social-emotional, cognitive and language</i>)	Increased knowledge and skills to support children's health and development
Child Changes	Increased number and percentage of children that receive recommended preventive care Increased number and percentage of children who have access to comprehensive health care	Increased number and percentage of children entering kindergarten with social-emotional skills	Increased number and percentage of children entering kindergarten healthy and ready for school, including: 1. physical well-being, health and motor development 2. social and emotional development 3. approaches toward learning 4. cognition and general knowledge, and 5. language, communication and literacy	Increased number and percentage of children who live in safe, stable and supportive families

Finally, the partnership effort called Kids Matter/Build continues to be led by the Department of Health, the Foundation for Early Learning, and the Head-Start-State Collaboration Office in the Department of Early Learning. The national Build Initiative is an effort of the Early Childhood Funders Collaborative, a group of foundations actively supporting state efforts to improve outcomes for young children. Kids Matter and Washington state are participating in the national Build effort. Kids Matter/Build partners continue to promote and support the development of early childhood systems using the Kids Matter framework. As this effort continues, there may be increasing opportunities to pilot efforts to enhance linkages with the Early Intervention Program; to help communities learn from one another; and to use those learnings to inform local and statewide policies and practices around Early Intervention and medical homes.

The Washington State Medical Home Leadership Network

The Washington State Medical Home Leadership Network (MHLN) promotes and provides practical support for medical homes --family-centered, comprehensive coordinated primary health care-- for children and youth with special health care needs. The MHLN is composed of volunteer, interdisciplinary parent-professional teams based in counties across the state; project staff; and a broad range of organizational partners. There are currently 20 teams with over 95 members, covering 24 of the state's 39 counties and the majority of the state's population. While teams do not provide care to individual children as part of their work with the MHLN, they do identify and carry out activities to address one or more unmet medical home needs in their county. King County has a MHLN team. [Note: most of this paragraph is taken verbatim from (Medical Home)]

MHLN team members, staff, and partners have long been interested in the issues addressed in this report. Across the state, and within counties, the MHLN has directly participated in efforts to improve and facilitate physician referrals to the EI Program, and to assure that families receive needed services in connection with a medical home. The Medical Home website is an excellent resource, providing relevant information for families, physicians and other providers. While a complete review of the work of the MHLN is beyond the scope of this report, it is important to note that the MHLN, both via the statewide staff and the King County Medical Home team, is an important partner for any King County efforts designed to enhance referrals to the EI Program, particularly those relating to primary care physicians/medical homes.

The MHLN agrees that continual efforts to educate, engage, and support physicians around referral of young children to the IE Program is needed. Overall, there is an impression that the system is still too complex, and that most doctors remain under informed. System changes which make referral more automated or easier would be very helpful. Standardized referral forms could be helpful to assure doctors provide needed information, and reduce the need for follow up calls which slow the process. Improved communication between the EI Program and the referring provider, including information about evaluation outcomes and the plan for services, would likely create a positive feedback loop that encourages doctors to refer to EI. The MHLN has experience from other counties where summary

reports to doctors were found to be very useful and well-received. Such efforts could be systematically implemented and evaluated in King County.

The MHLN strongly recommends that purposeful efforts continually be made by the Family Resources Coordinator and the EI Program to communicate with the child's primary care provider and medical home; no matter how the referral was initiated. Referral intake must include the name of the child's medical provider, and then automatically work to create a feedback loop. Even when families self refer, the EI Program should seek their permission to share information with the primary care provider. EI Programs should work under the assumption that such communication will be beneficial to the child and family; and always encourage families to share the information with their child's doctor. *"We have heard from many physicians, including those in King County, who feel that referring to EI Programs is like referring to a black hole. They don't know what happens to the child after they make the referral. This lack of communication seems to be a huge barrier to doctors making this crucial referral."*

The MHLN know that medical providers clearly need better information. The challenge is providing the information in effective ways to increase knowledge and induce changes in practice. The MHLN website already provides a lot of information, but most primary care providers do not access that material currently. Potential ideas for sharing information proactively include instituting "rotating Grand Rounds," a series of educational events in communities across the state that are tied into existing presentations which many primary care providers attend, and through which they receive Continuing Medical Education credits. The MHLN helps provide "Child Health Notes," written communications for medical providers about serving children with special needs. Many counties have regularly used these materials; King County has only recently begun to do so via Public Health-Seattle and King County. This might be one written direct-to-doctor venue for new outreach and education about IE Programs. It may be increasingly effective once physicians begin to recognize and use this new resource. In general, MHLN experience demonstrates that true change will likely require face-to-face encounters and practice specific training, not just written or web-based information. Particularly when it comes to encouraging medical providers to implement standardized developmental screening tools in their practices, experience has shown that doctors need fairly extensive support to do this, such as through a pediatric learning collaborative (described in a later section).

Ignoring for a moment the federal mandates around Early Intervention, and the rights of families to such services; the author wanted to gain an understanding of the importance of Early Intervention Program from the perspective a developmental pediatrician leading medical home and early intervention efforts. When asked directly about "who doctors should be referring to," or "whether all children with any developmental concern should truly be referred to the EI Program," Dr. Katherine TeKolste, the co-director of the MHLN, thoughtfully tried to address what she considers to be complex issues.

Dr. TeKolste reports that the data are clear that more children with developmental needs will be detected if early and continuous developmental screening is done with standardized instruments. Therefore, we as a county and state need to move toward a system where this screening occurs for all children. Secondly, because of the prevalence of multiple areas of developmental delay for many children with any concern, it is important that all children referred for evaluation have a broader look at

all their skills rather than one limited to a single area, such as speech or motor. Optimally this would be done by one or more professionals trained to assess development. The EI Program is set up to perform just such an evaluation. At the current time, the opportunity for most young children to obtain such a comprehensive evaluation is through the EI Program. Third, obtaining an evaluation and then receiving and coordinating all needed services is very often a significant logistical challenge that families and medical providers cannot navigate successfully without support. The EI Program automatically offers this care coordination via a Family Resources Coordinator, greatly increasing the chances that a family can successfully navigate the system and receive the spectrum of needed services. Provision of such care coordination services has been lacking in most other systems of care, both because of differing priorities of care coordination determined by different programs, and because of the frequent lack of reimbursement for such services.

The MHLN is interested in supporting efforts to enhance physicians' identification of potential delays, and successful referral of children into the IE Program. The staff believes that making serious headway within King County, or across the state, requires thoughtful discussion, strategic planning, and implementation through collaboration between multiple public and private programs and interested parties. The MHLN also recognizes many of the challenges expressed by EI Providers elsewhere in this report, including the need to better understand current referral patterns, current service provision by both the EI Program and private providers; current service capacity; and the potential to handle increased demands created by an effective effort to increase referrals. Systematic goal setting and data collection to evaluate efforts should take place. Finally, any new efforts should build from current and past efforts, leveraging together multiple areas in the worlds of health care, early intervention, early learning and family support.

Washington State Pediatric Learning Collaboratives

There is considerable national and local experience suggesting that it is very difficult for doctors and medical systems to institute changes in the way they provide care. In Washington state, we are fortunate to have Dr. Jim Stout, a pediatrician who has been at the forefront of practice Quality Improvement efforts, particularly those which involve learning collaboratives. While a thorough review of this topic is beyond the scope of this report, providing an overview of the process and experience in Washington state as it relates to doctors and Early Intervention is useful, and information obtained via an interview with Dr. Stout informed the following summary.

A Learning Collaborative is a data-driven, structured, quality improvement process which supports medical practices as they attempt to implement and measure practice change. Typically Learning Collaborative staff (like Dr. Stout and his team) direct and support the process which a number of medical practices pursue simultaneously, creating a "collaborative." Key staff from each medical practice comes together for educational sessions about the collaborative process, and about the topic of the change to be implemented. Practices are provided with a "change package" that includes evidence-based recommended standards of care and measures that will show whether changes are leading to improvement. They return to their practices with a plan to implement small changes in ways that can be quickly implemented and evaluated, and then repeatedly modify the process using locally collected data

until the desired changes are achieved. Throughout the process the practices are linked together to learn from one another, such as through electronic list serves, email, and phone calls. Each site receives direct support from the Collaborative staff through site visits and coaching calls. Support is also given to implement a data registry. This provides practices with a way implement a population-based approach, which provides proactive care via a prompting system and tracks progress.

Of specific relevance to this report, Dr. Stout and his team have led Learning Collaboratives including the implementation of developmental screening within medical practices in Washington state. Within the education provided to the participating teams during the collaborative process, one activity was deemed particularly helpful. A panel of people involved with programs to which physicians might refer, including the EI Program, presented to the medical teams. Following the panel, the local Family Resources Coordinator from the IE Program met individually with the medical practice team, introducing herself and explaining her role. This was extremely well received. According to Nicole Van Borkulo, who works with Dr. Stout to implement the Collaboratives, one doctor reported that this meeting alone *“revolutionized my practice.”* Ms. Van Borkulo believes that this approach was effective because doctors finally knew *“where to call, and had a name and a face”* to go along with the information. She believes that this strategy could be helpful on its own, bringing IE staff into clinics to share information and build relationships; and she suggests doing this in partnership with the Medical Home teams (see previous section).

Originally funded through a separate process with inconsistent support; the Pediatric Learning Collaboratives directed by Dr. Stout are now becoming part of the Washington State Collaborative to Improve Health. (Washington State Collaborative to Improve Health). This now connects Pediatric Learning Collaboratives to a long standing Quality Improvement process for managing chronic disease in adult medicine. In 2008 the children’s health tracks will include three focus areas: asthma, overweight prevention and treatment, and medical home. The medical home track may address issues related to Early Intervention. It is hoped that connecting funding and support for Pediatric Learning Collaboratives to a fairly consistent state-supported process for adult medicine will help sustain these Quality Improvement efforts over time. It is possible that future Pediatric Learning Collaboratives could be used to improve physician practices around the Early Intervention Program.

Kids Get Care and the King County Children’s Health Initiative

Under the auspices of Public Health-Seattle and King County, the Kids Get Care (KGC) program was tremendously effective in increasing access to primary care for low income children. Built on a model that encouraged “getting kids into care” and then sorting out insurance eligibility later, the program worked closely with multiple medical practices. This effort made significant use of community outreach by public health nurses and others, teaching the basics of looking for developmental and oral health “red flags,” as a method for encouraging families to get children into care. Onsite KGC staff helped practices connect with, engage, and enroll families into insurance and care. Kids Get Care also focused on preventive and comprehensive care, supporting model practices to integrate and co-locate medical, dental and mental health services whenever possible. Funded for multiple years through federal grants,

Kids Get Care was well received by many practices, who appreciated the staff and technical support KGC provided to help them change their practices, and care for more children comprehensively.

The Kids Get Care program has evolved into something known as the Children's Health Initiative. Funded through both county and private dollars, the CHI is expanding access to health insurance and connecting families with quality care which includes prevention. CHI is working with practices on quality improvement strategies, and would like to increase the routine use of standardized developmental screening tools. Partnering with and building from the statewide movement to "Cover all Kids" and get them into a medical home (see next section), the CHI is a potential partner for any new efforts to enhance physician practices around developmental assessment and referral to the Early Intervention Program. CHI staff is well versed in current state level efforts to expand developmental screening within primary care, including funding strategies and health care policy implications. CHI staff was previously very involved with the Pediatric Learning Collaboratives described earlier, as they partnered in the early efforts to implement developmental screening in primary care offices. Therefore, the CHI understands that significant behavior change will only occur through specific support for, and strategic implementation of, training for pediatric providers. Lisa Podell, manager of the CHI, believes that there could be a role for King County to implement and evaluate pilot training strategies which build from the learnings of the Collaboratives.

The Washington State Child Health Care Act

Finally, the state level policy efforts to "Cover all Kids" with health insurance by 2010 provide timely and very appropriate opportunities for efforts to improve the physician practice of developmental screening and referral to the Early Intervention Program. The passage of SSB 5093, the Child Health Care Act, in 2007 highlights this potential. This bill substantially broadens the original goal – moving from simple health insurance coverage, to assuring that all children have access to care within a Medical Home. The implementation of the Act also addresses the definition of a medical home, and begins the discussion about how quality care in a medical home can be implemented, measured, and rewarded. The bill required a report to the legislature outlining the strategies to be implemented and associated performance measures. That report, just issued on November 30, 2007, and information from one of the key participants in its development, Kirsten Wyses, informed the following sections.

The Children's Healthcare Improvement System Report (the CHIS Report) describes the bill as follows: *"Recognizing the need to improve children's health care services, the Washington State Legislature passed the Child Health Care Act in 2007. The Act expanded children's health care access, increased primary care payments and called for system changes to assure that all children get regular care from a Medical Home. Expansion of access and more funding are good first steps in improving health care services for children. Improved infrastructure, performance accountability and a pulse on consumer wants and needs are also important to create an improved system of care."* (Report to the Legislature: SSB 5093 Children's Healthcare Improvement System, 2007)

The CHIS Report lays out a five-year plan to assure the delivery of care within a medical home. Particularly relevant to this report is the specific inclusion of developmental screening as part of a

medical home. The goals outlined in the CHIS Report for the years 2009-2010 include increasing reimbursement to providers who use billing codes associated with standardized developmental screening tools. Providers will be reimbursed for using these tools to increase the early identification and intervention for developmental and behavioral delays. In addition, clinics will be encouraged to participate in a children's health care educational collaborative, and can be provided with other technical assistance to facilitate practice change. By 2011, practices will be required to adhere to at least two practice clinical guidelines, such as developmental screening. Therefore this CHIS Report recommends policies and reimbursements strategies which will encourage and support doctors doing development screening, and participating in the quality improvement activities which help them do so. These are some of the very activities described and recommended in other sections of this report.

The CHIS Report also describes the vital importance of educating the medical provider community. *"Successful models, such as the Chronic Care Collaborative managed by the Department of Health, academic detailing (e.g. visiting medical practices and sharing information), and novel approaches to education such as web-based training, are avenues for developing provider knowledge."* Finally, the CHIS report acknowledges directly the importance of connecting various efforts and systems together to achieve improved outcomes for children. *"The CHIS is a piece of a larger puzzle that involves improvements in public health, early learning, family education and continuous health care coverage. The workgroup believes that CHIS is a necessary piece of the foundation to improve the health of young children in Washington State."* Thus the CHIS Report directly supports recommendations made elsewhere in this report; including the leveraging of child health, early learning, and family support efforts together to improve outcomes for children across Washington state.

Review of the Literature: Developmental Services and Systems Change

"Children's success both in school and later in life depends on the quality of their early experiences and the ability of their parents and caretakers to anticipate and meet their developmental needs. Through regular contact with parents and young children, child health care providers can foster positive parenting behaviors, help to promote optimal development, and initiate early intervention when problems appear imminent" – The Commonwealth Fund (Commonwealth Fund, 2007)

Introduction

The efforts in King County and Washington State around engagement of doctors in early intervention occur in the context of growing interest in this issue around the country. With the use of the Internet, it is possible to go to major sources, like the Commonwealth Fund and the American Academy of Pediatrics, and relatively quickly download stacks of articles intended to inform processes to improve the identification of children with developmental delays. For the purposes of this report, more than 25 articles, summaries, and policy papers were reviewed. This section of the report will provide an overview of key concepts, experience and recommendations culled from these materials. The purpose is not to summarize or cite all that is available, but to bring key elements from this literature forward in practical ways to inform potential actions in King County and Washington state.

The need to improve identification and referral of children

While the complete case for change will not be reviewed in detail here, it is worth noting some of the basic statistics. It is estimated nationally that between 12-16% children have developmental problems, yet *"only one third of those - usually those with the most obvious conditions –are identified in pediatric practices prior to school entry"* (Halfon, 2005) *"Less than half of all children in the US appear to be receiving adequate developmental and psychological surveillance, screening for health risks, or anticipatory guidance."* (Chung, 2006) According to the 2000 National Survey on Early Childhood Health, only 57% of parents report that their child's development has ever being assessed during a pediatric visit. (Halfon, 2005) While understanding the situation is complex, overall the literature, and those professionals most involved with developmental issues, agree that 1) not enough children are being detected and referred in the early years of life; 2) many children are not experiencing the developmental surveillance and screening that is needed to identify those needing further assessment; and 3) pediatric health care practitioners are not playing as large a role in this process as they could or should.

Parents continue to express the need for support around developmental issues

In order to inform efforts to partner with parents around developmental issues, a 3-state survey of parents of children enrolled in Medicaid (including Washington state parents) was conducted using the "Promoting Healthy Development Survey-plus." (Bethell, 2002) This survey of 1900 parents/630 per state provided information about what preventive and developmental services children on Medicaid received, and their quality. The key findings of this study were that *"a significant number of children are at risk for developmental, behavioral and/or social delays; few children receive recommended*

comprehensive preventive and developmental services; parents have concerns that are not addressed by pediatric clinicians; and having a personal pediatric clinician or nurse makes a difference.” Additionally, the survey found that children at risk for developmental or behavior delay were significantly less likely than those less at risk to receive comprehensive services (14% vs. 25%).

Primary care physicians can provide several types of Developmental Services

If we agree that physicians can play an important role with families around child development, do we know what we want them to do? Some might say it is simple – just get doctors to refer families with any concerns to early intervention. While referrals are an important task for doctors, the potential roles of physicians with families are more complex, and have the potential for positive developmental impact in a number of ways. Halfon describes what is needed as *Developmental Services*, defined as “preventive pediatric services focused on optimizing healthy development.” (Halfon, 2005) Doctors routinely engage in well child care, and developmental services should be integrated within that setting. The four components of Developmental Services are:

Assessment—to identify developmental risks and problems

Education for parents on child development and promoting learning (commonly known by doctors as anticipatory guidance or health supervision)

Intervention for developmental concerns, either within the practice or by specialists or community programs (this is where early intervention services would fit)

Coordination of intervention and treatment services, including referral and follow up (including early intervention)

The typical primary care approach to developmental surveillance is not identifying children adequately

“Recent studies emphasize the importance of the interaction of brain development and environment on children’s developmental and behavioral outcomes. The tremendous adaptability of the brain in the first three years of life means that early treatment of delays leads to improved outcomes, whereas later intervention is less effective. In order to provide treatment to improve children’s outcomes, early identification of delays and sensory impairments (i.e., vision and hearing problems) is critical. (Sices, 2007)

Despite the case for early detection and referral of children with developmental concerns, a December 2007 review of current practice around developmental screening in primary care demonstrates continued minimal use of standardized developmental screening tools. The national rate of referrals for early intervention is at best 20% of the expected prevalence of developmental issues appropriate for referral. Because physicians see most children for multiple preventive visits during the first three years of life, primary care providers have the most regular access to children and families; and thus the opportunity to assess children’s development. While most physicians do not routinely use developmental screening tools; recent policy statements from the American Academy of Pediatrics

recommend them; so it is hoped this will help increase their routine use in primary care. (See later section)

The report makes a number of recommendations to promote early identification of developmental delays in young children:

1. Conduct research to understand the reasons for the gap between the prevalence of developmental conditions and their identification, document the effectiveness of physicians' developmental monitoring and screening efforts over time, and understand and address any negative consequences of developmental screening.
2. Address financial, educational, and other barriers to the use of developmental screening tools by physicians to increase their use
3. Train residents in pediatrics and family medicine to use developmental screening tools as part of the routine care of pediatric patients,
4. Develop high-quality screening tools which are available at no cost, and are compatible with electronic medical records.
5. Develop communication models need to help physicians discuss developmental screening test results with families.
6. Adding a 30-month preventive care visit to increase the number of opportunities to provide developmental screening and identify developmental delays at a critical time in young children's development.
7. Replicate successful models to promote developmental screening
8. Conduct federal and state level planning to anticipate and provide sufficient resources for the increase in evaluation and treatment capacity that will result when systematic developmental screening identifies a greater numbers of children with developmental delays.

It is difficult for doctors to change patterns of care around child development

Reviewing the articles and talking with parents make it seem obvious that it is important for doctors to play a bigger role in making sure children receive appropriate developmental services. Many parents and non-medical personnel frequently express frustration about the current situation and wonder "Why don't they just do a better job?" The simple answer is that it isn't easy to change – if it were, things would be different. A review of the literature presents many of the barriers reported by physicians. A better understanding of some of these issues will help inform processes and supports needed to inspire change within medical practices.

Many articles and surveys provide information about the barriers doctors see as limiting their ability to improve developmental care (Commonwealth Fund, 2007) (Chung, 2006) (Regalado, 2001)(Halfon, 2005). Given that doctors provide developmental services within the practice setting, and particularly within well child care, issues which impact the ability of doctors to perform high quality preventive services in general will impact developmental services. Common barriers to high quality preventive care often cited include: lack of continuity between provider and child/family, limited time within visits, and limited reimbursement for preventive services. In other words, doctors do not know children and families as well as they would like to, the time they spend with patients is too short, and insurance

payment structures have often tended to favor sick visits over well-child care. When it comes to development specifically, doctors additionally report that they are not as well trained in child development as they would like to be; they do often do not know how to use developmental screening instruments, lack the staff and processes to implement them, and are unable to receive payment for the added services; and that their communities often lack the resources to support families if they do identify needs.

Doctors and preventive care systems provide a way to reach many children

“Given the frequent contact that most parents have with their child’s health care providers, pediatric clinicians are in a unique position to ensure that children get the healthy start they deserve” (Bethell, 2002)

Despite the challenges of improving the provision of developmental services within the medical setting, doctors are likely to be the most common point of contact for families with young children. Therefore, improving services in these settings is likely to have an impact on the vast majority of children and families. Further, improving systems specifically within practices serving children whose insurance is provided by Medicaid is likely to be important. This is true for several reasons. The Early and Periodic Screening, Diagnosis and Treatment (EPSDT) provisions of Medicaid *“focus on current needs- physical, cognitive, social, and emotional – and future health. EPSDT services are specifically structured to promote children’s healthy development during the first five years of life”* (Schor, 2007) Further, the *“periodic and as-needed screening services are intended to detect developmental delays, while anticipatory guidance is designed to help parents meet children’s needs.”* Nationwide about 25% of all children are served by Medicaid. In Washington state, about 50% of all children under the age of 6 are served by Medicaid (HRSA, 2006). Thus, enhancing the quality of developmental services for those on Medicaid will impact almost half of young children in our state; and likely include many of those considered most at risk for developmental, behavioral, or social delay.

Pediatric practice guidelines only recently began recommending formal developmental screening

It is important to understand that it is only recently that the American Academy of Pediatrics (AAP) formally endorsed the stance that standardized developmental screening tools should be routinely used in primary care. In 2006, the AAP released its policy statement, *“Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening.”* (American Academy of Pediatrics, 2006) The policy statement is relatively complex and lays out the various roles for physicians. Clear distinctions are made between three related processes. “ (1) surveillance, the process of recognizing children who may be at risk of developmental delays, (2) screening, the use of standardized tools to identify and refine that recognized risk, and (3) evaluation, a complex process aimed at identifying specific developmental disorders that are affecting a child.” The policy says that surveillance should be incorporated into every well-child visit; and that standardized screening tools should be used for all children at the 9-, 18-, and 30-month visits. Since the release of this guideline there has been increasing awareness of these issues, but there are still substantial barriers to its full implementation in most practices.

Just two months ago, the AAP released a clinical report “The identification and evaluation of children with autism spectrum disorders,” a more than 30-page document. (American Academy of Pediatrics, 2007) It was released alongside an Autism “toolkit” for doctors, with much fanfare at the AAP’s annual National Convention and Exhibition. The increasing prevalence of Autism Spectrum Disorders, and the accompanying understandable concern of parents and the public, has heightened attention to this report. Within the many recommendations is a reaffirmation of the previous policy statement around developmental screening, and the additional recommendation to administer an autism-specific screening tool at the 18 and 24 month visits. There is recognition by the AAP and its members that implementation of these recommendations will require training, support, and reimbursement.

States are working with physicians to improve the quality of children's health care.

There is growing recognition that improving the quality of children’s health care, including developmental services, is a complex, multi-systems change process. There are national efforts to support public-private collaborations which enhance quality across states. A recent article reviewed the efforts of five states, including Washington, and summarized the findings. (Pelletier, 2006) Several different models were used to implement change, including pediatric learning collaboratives, which were described earlier. From these efforts evolved some lessons which can help inform future efforts to impact systems changes with physicians to improve health care for children.

Five common lessons were identified:

- 1) Involve physicians in all aspects of development and implementation
- 2) Keep the needs and interests of providers central
- 3) Help physicians connect with community resource agencies as part of the process
- 4) Start with a small group of physicians or practices, track progress, improve processes, and build both support and demand for the work; and
- 5) Build flexibility into efforts to meet the needs of different practices

States are working with physicians to promote children's healthy mental development

The consortium known as ABCD II was *“formed to provide five states with an opportunity to develop and test strategies for improving the care of young children at risk for or with social or emotional development delays, especially those in need of preventive or early intervention services.”* (Kaye, 2006) The projects promoted pediatric use of validated screening tools and helped providers integrate the tools into their practices; identified and facilitated appropriate referral to follow up services; and identified and addressed policy barriers. They accomplished this through the formation of partnerships and the use of quality improvement strategies. While this effort focused specifically on social-emotional development, the activities and lessons learned are relevant to early child development generally. The projects demonstrated that standardized screening tools can help ensure healthy development; that screening must be accompanied by access to follow up services; and that project demonstrations can inspire and test policy change. In the process, states learned that *“developing successful partnership with providers takes effort and a willingness to follow as well as lead.”*

Strategies for improving the quality of preventive health care and developmental services

“Targeted policy steps to create a comprehensive system, including the creation of national standards and tools, improved pediatric training, an enhanced reimbursement system, quality improvement initiatives, and heightened parental involvement and awareness will be necessary to meet the needs of young children and their families.” (Halfon, 2005)

The need for improvement in preventive health care and associated outcomes is clear; but the process to get from here to there is far from simple. This article reviews the issues and presents six recommendations which are important to the goal of optimizing child development. (Halfon, 2005)

1. Implement routine use of standardized developmental assessment tools
2. Create a community-wide, comprehensive infrastructure
3. Measure and compare quality of developmental services
4. Create public-private quality improvement partnerships
5. Provide adequate reimbursement for developmental services
6. Raise parents expectations

Each of these recommendations is complex within itself. For example, implementing routine standardized developmental assessment tools requires practices to integrate a way to elicit parent concerns and to assess children; and then to use those results to guide interactions with parents. The assessment process has two parts- screening to identify children with risk for delay, and the in depth assessment which follows to fully understand the child’s status. At the community level there must be an effective system for the comprehensive assessments, as well as for the provision of any needed services. The article points out the importance, and challenges, of effectively engaging physicians in the whole process. *“A key step in making a referral system work is convincing pediatric professionals, especially pediatricians, to use it. Pediatric providers must be aware of resources and confident in the services provided before they will readily refer their patients. Putting together a directory of available agencies is not enough; building trusting relationships between medical and community providers is critical to a communitywide system’s success.”* (Halfon, 2005)

Another article specifically addresses strengthening childhood development services in the health care system (ref 18), describing how promising practices to improve child development services are being implemented at three levels: primary care , community, and state. Within primary care settings, efforts are occurring to improves practices internally, and to build connections with community systems and services. At the community level agencies can serve as a bridge between state programs and policies and what occurs in primary care offices. This might include creating linkages between providers to strengthen child development services and referral mechanisms; strengthening tracking and assessments systems; educating health providers about community early childhood development resources; and improving referral and feedback loops between agencies and providers. State level efforts and policies can support community efforts. For example, they can help inspire and support new child development service practice models at the community level. They can also facilitate training and

continuing education on early childhood development and related services for health providers, community agencies, and others.

The importance of linkage, beyond just referral

The comprehensive report “Beyond Referral: Pediatric care linkages to improve developmental health” emphasizes more specifically the concept of linkage, defined as: *“connecting the child to needed services and supports while also staying connected to the child. More specifically, linkage indicates the act of connecting the child and family to needed developmental services and supports, whether within the practice setting or beyond.”* (Fine, 2006)

The authors reviewed experiences with linkage in communities and states, and organizes the linkage strategies into three broad categories. **Practice-Wide Systems Change** describes strategies that transform the way practices are organized to deliver developmental care. Examples include developmental screening and referral to follow up systems; and improving practice through quality improvement/systems change processes. **Service Provider Partnerships** describe strategies that strengthen the relationship between pediatric practices and existing community services. Examples include collocation of services, and improved networking and information sharing to assess system gaps and collaborate to address them. **Community-Wide Systems Change** describes strategies that enhance or transform existing community or state systems of care. Examples include new community or statewide programs that improve linkage and fill gaps in needed developmental services, such as centralized referral/linkage resources; and systemwide developmental training programs for primary care practices which enhance developmental expertise, introduce practice-wide systems change approaches, and emphasize the importance of linking to other community services and systems.

The report concludes with seven recommendations for enhancing developmental care linkages in communities, states, and nationwide:

1. Use quality improvement strategies at the practice level.
2. Adapt well-child care systems to increasingly promote healthy child development.
3. Engage professional associations and umbrella agencies to identify and link developmental resources within communities.
4. Promote co-location of public services with pediatric practices, and other innovative and cost-effective ways to maximize the effective use of developmental care resources
5. Promote mid-level (non-physician) developmental assessment and referral/linkage capacity at the community or regional level.
6. Support training for pediatricians and other primary care providers to help them implement practice-based systems change for developmental care.
7. Identify and promote key policy changes, including those that improve financing and sustainability of community systems for developmental care.

Help Me Grow, an example of a comprehensive linkage model

While the components of developmental care described thus far seem very comprehensive, Connecticut has led the states in providing a single point of entry which takes referral to the next step, assuring that families are connected to all needed services. The program, called Help Me Grow *“trains and supports pediatric practitioners in screening and assessing potentially at-risk children and in eliciting parents’ opinions and concerns and helps match children and their parents with needed services through a centralized referral and case management system.”* (Dworkin, 2006) Provider trainings are individualized to meet the needs of practices. *“The most effective training is focused on a simple message and tailored to individual practices. HMG trainers make short presentations in providers’ offices, offering lunch, continuing education credits, and free resource kits. They involve the entire office team, including nurses, doctors and receptionists; and emphasize office-based change using clinical information and practical tools.”* HMG simplifies the complex process of connecting families to resources by offering a single point of entry to the system via toll free line; and then providing dedicated staff to make connections between families and community-based resources. The *“HMG liaisons...‘make sure the dots are connected’ within the community.”* The model has been extremely successful in improving referrals; and moderately so in improving developmental screening in the office setting.

Policy implications for improving child development services

Many of the recommended system changes described in this report have connections to federal, state and local policies or practices. Another summary article describes state policies from eight states, including Washington, which have impacted child development services (Kaye, May, & Abrams, 2006) The eight ABCD states participated in a learning consortium with two main objectives: 1) Improve the identification of young children with or at risk for developmental delays by promoting the use of an objective, standardized screening tool; 2) Improve families’ access to follow-up services, including assessment, referral and care coordination. The policy changes used within the states could be summarized in three areas: program coverage, reimbursement, and performance. Improving program coverage often related to insurance eligibility and benefits. Within Washington state new well child encounter forms were created to help structure developmental surveillance by providers. Improving reimbursement included reimbursing primary care providers for doing developmental screening, and providing financial incentives to health plans for increasing use of developmental screening tools. Efforts to improve performance, or quality of care, included creating standards; implementing quality improvement projects to support referral and/or coordination of care, and ‘unbundling’ procedure codes for developmental screening to make it possible to track progress. Reviewing the eight states generated a list of four factors which seemed to help ensure success:

Success factors

- A strategic plan (clarity about goals, objectives, policy priorities)
- Broad stakeholder participation (all agencies)
- Grounding proposed improvements in experience (pilot test w/ local physician practices; collect data to show progress over time)
- Creating opportunity (build on complementary state and local initiatives)

Summary

The Early Intervention Program described in this report is a complex system involving federal, state and local regulations. The Infant Toddler Early Intervention Program in Washington State contracts with the King County Early Intervention Program to provide services locally. Medical Providers are mandated to refer families to EI systems appropriately, and to advise families of their rights. The King County Early Intervention Program contracts with local agencies to provide services to families, and many of these EI providers informed this report, sharing the complex process from referral through to a complete Individualized Family Service Plan. The EI Program has many strengths, most notably the passion of all the people involved in caring for children. This report focuses on areas for potential improvement, calling on the collective wisdom of those on the ground, setting the stage for the potential to serve even more children and families effectively.

Early Intervention Provider Perspectives

Early Intervention contractors believe some children are being referred too late, and describe a complex situation with incomplete data. EI providers have theories for why referral numbers may be lower than desired. They believe that some children are not being referred in a timely fashion (true late referrals), some are not deemed eligible for services once they are referred, some are being referred to services that are not included in the ITEIP data, some are being referred to the EI system after receiving services in a private setting, and some children are being served without having their data included in the ITEIP system. EI Providers believe that it is imperative that King County gain a true understanding of this situation as part of the overall strategy to improve referrals.

Early Intervention Providers believe that doctors can be good partners, and that doctors have a role in improving the EI referral process. Early Intervention providers have variable levels of interaction and communication with doctors around their services, both generally, and around specific children and families. While most EI Providers believe that direct outreach to doctors would facilitate information sharing, build relationships, and encourage referrals; few currently do this outreach; most often due to staffing restraints. Most EI Providers report communication with doctors around referral intake, though few have formalized referral support processes, such as referral forms. Many EI Providers report communicate with doctors after a child has been evaluated, but these processes are not consistent; with some using specific follow up forms to streamline communication processes. Similarly many EI Providers report communicating with doctors after Individualized Family Service Plans are complete. They believe the full reports are cumbersome, and that a summary would be more helpful to doctors. However, many do have the staffing to create such a summary themselves.

EI providers believe that doctors need a better understanding of the EI system and how it works, and have ideas to encourage and support appropriate referrals from doctors. Providers would like to see a collaborative approach to educating physicians, with some pieces being led centrally by King County; and others by EI Providers in direct face-to-face interactions with Medical Providers. EI Providers believe there is a need for specific strategies which educate doctors countywide about the EI Program. They do not think doctors understand the difference between the EI Program and other services; and believe

that educational efforts should provide a basic understanding about who should be referred, the comprehensive evaluation process, the creation of the IFSP, the provision of services in Natural Environments, and the role of Family Resources Coordinators. EI Providers experience demonstrates that developing personal relationships with physicians enhances referrals, and they would pursue this if staffing would allow. EI Providers also recognize that their systems could more effectively communicate with physicians throughout the process of an individual child's progression through the EI Program, and that procedures (like summary reports and other forms) might enhance relationships and future referrals.

While EI Providers believe the EI Program provides many needed services to families, they also recognize areas where system change could help them more effectively serve families. They spontaneously noted needs for themselves or the system in the following areas: baseline referral data at the population level; ITEIP computer/data system issues; eligibility determination; service capacity; payment for services; staff training; program quality measurement and improvement; competition and collaboration; school district involvement; and system financing.

EI Providers are interested in improving the EI Program overall and offer several specific suggestions. They suggest methods for better assessing referral and service rates, and improving data sources. They would like technical assistance around eligibility generally to assure consistency across programs; and specifically around young children and premature infants. They believe there is a need to document current and predicted capacity needs for the programs, and for the system as a whole. Anticipating and planning for the impact of increasing referrals is needed before significant effort to increase referrals are implemented.

Medical Provider Perspectives

Doctors share many the same views as Early Intervention Providers. They believe that that some children are being referred too late to the Early Intervention Program. They believe they are partly responsible for late referrals, and that they have a role in improving the process. Most doctors and clinics refer families to the Early Intervention Program, but doctors do not understand the Early Intervention Program well. Specifically, doctors are not familiar with the role of FRCs/Family Resources Coordinators or with Individualized Family Service Plans (IFSP). Doctors and clinics make referrals to the Early Intervention Program in a variety of ways, and many do not know about the central referral option, or what procedures the Program would prefer.

Once doctors do refer to the EI Program, they receive insufficient follow-up and information exchange about the child and family. Doctors would like to know if patients they refer make an appointment, and the results of an evaluation. They want to know what services are recommended, and if the family participates in them. Doctors see many times when families have difficulty following through, and believe that further information sharing between themselves and the EI Program would help increase the likelihood that families can complete the process. Doctors are interested in further information and resources about the Early Intervention Program, and in general do not feel they know how well the Program currently works.

Doctors have ideas to make it easier for them to refer families to the Early Intervention Program. They are interested in educational efforts which increase their understanding and awareness of the program, how it works, and what they should expect. While many would welcome access to written and electronic information, they believe they would benefit most from in person “in services” by the EI Program in their offices. In addition to the need for their own understanding, doctors believe that the system is overly complex and difficult to access, and that system changes may be needed to assure effective referral and evaluation processes and high quality services. Perhaps most importantly, many see a huge need for direct support to families throughout the process, a case management approach which walks the families through the process from start to finish. Since doctors are not familiar with FRC’s, it may be that what they hope for already exists; but they are simply under-utilizing the system.

Washington State Opportunities

The Early Intervention Program and efforts to engage physicians more effectively with it have considerable opportunities to engage with other relevant efforts in Washington state. Doing so will allow the EI Program to leverage existing interest in young children and strategies to improve outcomes. The momentum around Early Learning and the Kids Matter framework offer opportunities to see connections between systems, and to define strategies around desired outcomes being used across the state. The Washington State Medical Home Leadership Network has connections with physicians, extensive knowledge about this subject area, and an interest in the same outcomes. The Washington State Pediatric Learning Collaboratives have specifically implemented Quality Improvement strategies around Developmental screening, and may have future opportunities to do so. Kids Get Care and the King County Children’s Health Initiative efforts to increase children’s access to high quality care, including developmental screening and services, provide both relevant experience and potential future opportunities for direct partnerships to implement strategies within King County. Finally, the Washington State Child Health Care Act provides very direct policy and funding opportunities around medical home and developmental screening. King County would be wise to build partnerships with many, if not all, of these efforts. Doing so can help facilitate more comprehensive strategies, and potentially tap into other funding sources and opportunities to leverage policy and positive outcomes in as systemic way.

Review of the Literature: Developmental Services and Systems Change

There vast size of the body of literature relevant to this report confirms both the need for, and the complexity of, creating systemic change around Early Intervention services, including the role of physicians. Parents continue to express the need for support around developmental issues. Despite the challenges, primary care physicians have a significant role to play around child development, particularly given their ready access to most young children. Unfortunately, the typical primary care physician approach to developmental surveillance is not identifying children early enough, and there are many practices barriers to change, including lack of continuity, time constraints, and reimbursement issues.

Developmental services in doctors' practices can be described as encompassing four areas: Assessment-to identify developmental risks and problems, Education for parents on child development and promoting learning, Intervention for developmental concerns, and Coordination of needed services. From a developmental perspective, doctors are generally not as well-trained in child development as they would like to be, including lack of comfort with standardized developmental screening tools. Pediatric practice guidelines only recently began recommending formal developmental screening. There is broad recognition that education and quality improvement support is needed in order for doctors to embrace needed change around developmental services.

States are working with physicians to improve the quality of children's health care. There is growing recognition that improving the quality of children's health care, including developmental services, is a complex, multi-systems change process. Important lessons to keep in mind in instituting change efforts are to: involve physicians in all aspects of development and implementation, keep the needs and interests of providers central, help physicians connect with community resource agencies, start with a small group of physicians or practices, and build flexibility into efforts. States are also working with physicians to promote children's healthy mental development; demonstrating that standardized screening tools can help ensure healthy development; that screening must be accompanied by access to follow up services; and that project demonstrations can inspire and test policy change.

Strategies for improving the quality of preventive health care and developmental services make similar recommendations: Implement routine use of standardized developmental assessment tools; create a community-wide, comprehensive infrastructure; measure and compare quality of developmental services, create public-private quality improvement partnerships; provide adequate reimbursement for developmental services, and raise parents expectations. Another article describing how promising practices to improve child development services are being implemented at three levels: primary care , community, and state. A reported focused on the concept of "linkages" talked about the need for Practice-Wide Systems Change, Service Provider Partnerships , and Community-Wide Systems Change All of these efforts are slightly different, but complimentary ways of describing the needed system changes. They affirm the complexity of the pieces of developmental services, including referrals; and how the EI System should be integrated and connected with health care systems and community supports for families; and with quality improvement strategies within each.

Almost everything discussed in this report has potential policy implications. A review of multi state efforts to improve child development services determined the following success factors: A strategic plan, broad stakeholder participation, grounding proposed improvements in experience, and creating opportunity by building on complementary state and local initiative.

Taken together, the information provided in this report provides many opportunities for strategic interventions to improve the EI Program, particularly around connections with physicians. The next step is a strategic process to decide how to proceed, and the recommendations in the following section can help inform this.

Recommendations

The following recommendations are based on needs identified by stakeholders, most of which were expressed by early intervention providers, medical providers, and other stakeholders alike. They are all also consistent with the findings noted in the research review section, suggesting that King County providers recognize the same issues that have been noted elsewhere across the country. While the primary task of this report was to determine and recommend strategies to increase medical provider referrals, it would be counter-productive to do so without having the capacity to accept those referrals and meet families' needs effectively. Thus this report contains recommendations about data needs and broader systems change efforts which must be considered.

It is possible to begin strategies in both areas simultaneously, if this is done in a planful way, with careful monitoring of the impact of the strategies. By implementing small pilots, for example, it may be possible to quickly see the impact of a given strategy, and whether it is likely to backfire by overwhelming the capacity of the system. That said, it is imperative that all children who need services are identified. By careful monitoring of referrals, responses, and any bottlenecks in the system, King County will be able to provide data which justifies the need for expanded funding to increase service capacity. Without such data, it is more difficult to make the case for increased support for the Early Intervention Program.

The following strategies are not listed in a particular order. How many of these to initiate, and in what order, will need to be determined by the SOAR Early Intervention Action team and its partners. Choices will necessarily be made based on a combination of desired outcomes, feasibility, potential impact, and cost considerations. The goal is to provide a menu of possible next steps which are thought to be necessary and likely to be effective and embraced by those whom they impact.

Early Intervention and Medical Provider Strategies

Implement a plan to educate primary care Medical Providers about the Early Intervention Program

- Process
 - Engage all EI providers in the conversation along with the county DDD
 - Learn from existing successful strategies, consider replication, and/or other pilots
- Content
 - General system information and processes- what is offered, how it works for families
 - Referral processes – how to help families access the system
- Mechanism to consider
 - Countywide basic materials created and placed on website, and in printed form
 - Program specific information, consider streamlining across programs
 - Emphasize face to face encounters, modeled after existing successful programs; seek to support and expand these, and document feedback post training from providers

Implement a plan to educate hospitals and NICU programs about the EI Program

- Content
 - General system information and processes- what is offered, how it works for families
 - Referral processes – how to help families access the system
- Mechanism to consider
 - EI staffing connecting with hospitals around discharge planning
 - Education of birth center staff, NICU staff, therapists, etc.

Implement a plan to improve and systemize communication between Early Intervention Providers and Medical Providers at key touch points

- Referral initiation: consider standardized forms for doctors to use
- Referral follow up: create a way to inform doctors if a connection was made with the family
- Evaluation process follow up: evaluation reports or summaries, consider standardized forms
- IFSP follow up: implement process to create standardized IFSP summary forms that are feasible for EI providers

Support EI Providers with technical assistance

- Provide technical assistance around eligibility screening, in general, and specifically around very young children and premature infants
- Provide technical assistance around measuring service quality
- Provide technical assistance around planning for increased capacity

Support training for primary care providers to help them implement practice-based systems change for developmental care

- Pediatric Learning Collaboratives
- Pilot “mini-collaboratives” or other strategies
- Collaborate with medical home efforts which support providers

Identify and promote key policy changes, including those that

- Improve financing, quality, and sustainability of medical provider services around development (e.g. developmental screening).
- Improve financing, quality and sustainability of early intervention provider services around development (e.g. staffing needs for evaluation and service provision, and for communicating with medical providers).
- Assess and support additional capacity needs within the EI Program

Systems Level Strategies

Determine goals within the Early Intervention system through partnership efforts which build on known likely “success factors” including

- A strategic plan (clarity about goals, objectives, policy priorities)
- Broad stakeholder participation (all agencies and stakeholders)
- Grounding proposed improvements in experience (pilot test w/ local physician practices; collect data to show progress over time)
- Creating opportunity (build on complementary state and local initiatives)

Collect King County data to help inform all strategies, such as

- Capacity data: current capacity for each programs, the 800#, and total county capacity
- Referral data: brief review of referrals as they come to assess if they are “late”
- Private services data: acquire data around children in private services

Help monitor and determine appropriateness of referrals

- Work with partners like the MHLN to clearly define for doctors who should be referred
- Monitor referrals and outcomes and reassess as needed

Plan for response to increased referrals, and monitoring of impact

- Evaluation and service capacity planning system wide
- Plan to monitor referrals, evaluation, IFSP creation, and service provision processes as referral increase

Leverage medical home and early learning efforts

- Encourage pilots to be implemented in King County
- Facilitate communication and collaboration between early learning and health/medical home efforts within King County

Recognize the larger systems issues and context of the Early Intervention Program within Early Childhood Systems (including both Medical Home and Early Learning)

- Continue to bring these efforts to both Medical Home and Early Learning discussions
- Advocate for the inclusion of the Early Intervention Program in all planning around family connections to community resources

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 Steve Dagg, MD, Family Practice, Swedish West Seattle
 Ben Danielson, MD, Pediatrician, Odessa Brown Children's Clinic, Seattle
 Nancy Danoff, MD, Pediatrician, Eastgate Public Health, Bellevue
 Jay Fathi, MD, Family Practice, 45th Street Clinic, Seattle
 Ellie Graham, MD, Pediatrician, Harborview Medical Center, Seattle
 Sue Hott, MD, Pediatrician, Swedish Children's West Seattle
 Diana Linder, MD, Pediatrician, Locums Eastgate Public Health and Columbia Health Center
 Ben Danielson, MD, Pediatrician, Odessa Brown Children's Clinic, Seattle
 Cathy Pew, MD, Pediatrician, Community Health Centers of King County- Federal Way (formerly)
 Michelle Terry, MD, Pediatrician, UW Medicine Kent-Des Moines
 Jeff Wright, MD, Pediatrician, UW Medicine Roosevelt, Seattle
 Lenna Liu, MD, Pediatrician, Odessa Brown Children's Clinic, Seattle

Interviews with Early Intervention Providers and Administrators

Kim Gerdes and Enrica Hampton, Kindering Center
 Sandy Duncan, King County Lead FRC
 Sandy Carlson and Linda Thompson, SKIP/Kent Children's Therapy Center
 Megan Cromar, Encompass
 Cheryl Buette-meier and Judi Moore, Boyer Children's Center

Interviews with Early Intervention Administrators and SOAR partners

Leilani Dela Cruz, King County Developmental Disabilities Division
 Sandy Morris, the Infant Toddler Early Intervention Program
 The SOAR Prevention/Early Intervention Action Team
 Harla Tumbleson, SOAR
 Karen Walker, the Infant Toddler Early Intervention Program
 Jan Wrathall, King County Developmental Disabilities Division

Interviews related to Washington State Opportunities

Lorrie Grevstad, Kids Matter/Washington State Department of Health
 Aileen Hammar, Children's Hospital and Regional Medical Center
 Kate Orville, Medical Home Leadership Network
 Lisa Podell, King County Children's Health Initiative
 Jim Stout, MD, Child Health Institute, University of Washington
 Katherine TeKolste, MD, Medical Home Leadership Network
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 Kirsten Wyses, King County Children's Health Initiative; and statewide Medical Home workgroup

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